

**Persistent Taboo
Understanding Mental Illness and Stigma among Indonesian Adults
Through Grounded Theory**

by

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ABSTRACT

This study explored stigma associated with mental illness among Indonesian adults living in Indonesia. It investigated how mentally ill adults (both mentally ill patients and mental health nurses) perceive mental illness and how they respond to stigmatization on a daily basis. Given the current state of knowledge with regards to the meaning and process of stigma and mental illness among adults in Indonesia, a constructivist grounded theory was considered to be the method of choice for this study. We recruited 15 nurses and 15 patients to participate in the study; all from a psychiatric hospital in Indonesia. Data collection methods involved semi-structured interviews with the 30 participants as well as mute evidence, field notes and memos. Data analysis occurred over a period of six months. In keeping with the basic principles of a grounded theory method (Charmaz, 2006) as well as Paillé's (1994) structure for data analysis which are congruent with Charmaz's principles and include stages of codification, categorization, linking categories, integration, conceptualization, and theorization, 5 discrete but interrelated categories were produced: 1) treatment of mental illness; 2) violence; 3) fear; 4) constructing cursed citizens; and 5) stigmatization.

Research results show that the experience of stigma for mentally ill patients in Indonesia is pervasive and impedes mental health services utilization. The stigmatization of mental illness is manifested by family members, members of the community, mental health professionals and staff, and also by governmental institutions and the media. Stigmatization is characterized by violence, fear, exclusion, isolation, rejection, blame, discrimination, and devaluation. Moreover, because of their (mis)understanding of mental illness, patients and families turn to alternative treatments provided by non-professionals (shamans, Islamic leaders, paranormals and traditional Chinese medicine); these individuals play a central role in supporting and offering solutions for someone suffering from a mental illness.

In Indonesia, stigma affects mentally ill individuals at many levels. Until stigma associated with mental illness is addressed nationwide, those suffering from mental illness will continue to suffer and be prevented from accessing mental health services. As the results of this study have shown, patients seeking treatment experience violence and fear. Families and their mentally ill relatives have been expelled by their community, or have simply disappeared. Both physical and psychological abuse and humiliation have led to patients being avoided, rejected, and neglected, and thus isolated, hidden, or abandoned to the streets. There is a pressing need to combat mental illness stereotypes in Indonesia and health professionals, namely nurses, government agencies as well as the media must play a pivotal role in this process.

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CHAPTER 1

RESEARCH PROBLEM

1.1. Introduction

Mental health is the successful performance of mental functions that result in productive activities, in fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. According to the World Health Organization [WHO] (2011b), “mental health is a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and can make a contribution to her or his community” (p.1).

Mental health problems become mental illnesses when “signs and symptoms of sufficient intensity or duration meet the criteria for any mental disorder.” A mental illness is defined as “collectively all diagnosable mental disorders or health conditions that are characterized by alterations in thinking, mood, or behaviour (or some combination thereof) associated with distress and/or impaired functioning” (U.S. Department of Health and Human Services, 2001 p.7). Mental illnesses are generally a combination of how people feel, act, think, and perceive. They are associated with particular regions or functions of the brain or the nervous system. According to Kitchener and Jorm (2002), there are different types of mental illnesses, some of which are common, such as depression and anxiety, and some not so common, such as schizophrenia and bipolar disorder. In addition, evidence has shown that mental illnesses are related to many chronic diseases including diabetes, cancer, cardiovascular disease, asthma, and obesity. They also appear to be related to the many risk behaviours, such as physical inactivity, smoking, excessive drinking, and insufficient sleep, that often lead to chronic disease (Chapman, Perry and Strine, 2005). A mental illness refers

to an actual illness, while a psychiatric disability refers to the impairment the individual experiences as a result of mental illness (Hawari, 2001).

In most countries, over a third of people report problems at some time in their life that meet the criteria for diagnosis of one or more common mental illnesses (WHO International Consortium in Psychiatric Epidemiology, 2000). By 2020, some authors predict that 15% of the global population will have mental problems (Harpham et al., 2003). According to the WHO (2011a) mental health disabilities account for 37% of global healthcare costs that are related to non-communicable illness. Much of the economic burden of mental illness, however, is not the cost of care, but the loss of income due to unemployment, expenses for social supports, and a range of indirect costs due to chronic disabilities that begin early in life (Bloom et al., 2011). Mental illness is a double-edged sword – those affected not only have to deal with the symptoms and disabilities of their illness but also with discrimination, or stigma (Kapungwe et al., 2010). It is a widespread problem and is part of the experience of having a mental illness (Borinstein, 1992; Corrigan, Markowitz and Watson, 2004; Crisp et al., 2000; Link et al., 2001).

The word "stigma," which originated in ancient Greece, described the marking or branding of slaves (Falk, 2001). It was also used to describe body sign(s) that indicated something bad about the moral character of a particular person or group. Goffman (1963) defines stigma as an “attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one” (p. 3). Link and Phelan (2001) define stigma as the co-occurrence of its components of labeling, stereotyping, separation, and status loss and discrimination. Stigma is the most important barrier to quality of life of mentally ill patients and family members. Stigma deprives people of their dignity and

interferes with their full participation in society (Anglin, Link and Phelan, 2006). It interferes with the potential of the individual to be part of a supportive social relationship and to openly identify with others about their mental illness. Stigma results in prejudice and leads to fear, suffering, low self-esteem, mistrust, low self-efficacy, and violence. It is manifested in negative attitudes, behaviours, and feelings toward stigmatized people or groups. A person with a mental illness may feel the effects of social rejection, isolation, and discrimination for most of his or her life (Corrigan, Markowitz and Watson, 2004; Link et al., 2001; Nelson, 2002). Stigmatization of mental illness creates a vicious cycle of discrimination and social exclusion not only for those who suffer from a mental illness but also for all of those who are associated with them. This discrimination leaves many people unable to seek treatment, and prevents the development of appropriate policies in the field of mental health (Harpham et al., 2003; WHO, 2001). Stigmatizing attitudes toward people with mental illnesses and their healthcare professionals will jeopardize patients' recovery because they generate institutional discrimination and community isolation.

Stigma has been studied and explored from multiple perspectives and disciplines. Studies in Western countries show that the associations of mental illness with drug and alcohol abuse generate sentiments of blame and condemnation, holding those affected responsible for their illness (Sartorius, 2007; Schulze, 2007). Other studies also view causation as strongly associated with discriminatory attitudes towards people with mental illnesses (Crisp et al., 2000; Gureje et al., 2005). Many authors have probed the conscious mechanisms that produce boundaries between people with mental illnesses and so-called normal people. For example, only about 50% of Canadians would tell friends or coworkers that they have a family member with a mental illness, compared to the 72% who would

discuss diagnoses of cancer or the 68% who would talk about diabetes in the family (Canadian Medical Association, 2008).

In developing countries, stigma is ubiquitous and insidious across the entire society. One study in Zambia revealed that stigma was directed not only towards those labeled as mentally ill but also extended to family members across generations and even to psychiatric hospitals themselves (Kapungwe et al., 2010). Very little attention is devoted to addressing the negative beliefs and behaviours surrounding mental illness in South Africa (Hugo et al., 2007). This corroborates findings from other studies that also demonstrate that this kind of discrimination extends to both family members and to those who work in psychiatric hospitals (Byrne, 1997; Lauber and Sartorius, 2007; Rosen, Walter, Casey and Hocking, 2000). In addition, the media has often depicted people with mental illness as violent, erratic, and dangerous (Diefenbach, 1997; Granello, Pauley and Carmichael, 1999; Monahan, 1992; Wahl, 1995).

According to the Ministry of Health [MOH] of Indonesia (2013), the prevalence of severe mental disorders is 1.7 per 1000 population and for mild mental disorders is about 60 per 1000 population. Most people with severe mental illnesses live in Yogyakarta, Aceh, South Sulawesi, Bali, and Central Java provinces. According to data from 33 psychiatric hospitals (Rumah Sakit Jiwa or RSJ), 2.5 million people had severe mental illnesses in 2012 (Rudi, 2012). The causes of mental disorders in Indonesia are related to biological, socio-demographic, and psycho-educational factors. Socio-demographic factors include age, sex, population density, education, marital status, occupation, family economics, and perception of social rank.

The treatment of mental illnesses in Indonesia is not optimal (Maramis, 2007). Less than 1% of Indonesia's total healthcare budget is directed towards mental health services, the lowest in Asia, and the country has one of the lowest ratios of psychiatrists per capita in the world (Irmansyah, 2010). Over half of these psychiatrists work in the capital city of Jakarta (Meshvara, 2002). According to Minas and Diatri (2008), the quality of hospital mental health services is also not ideal. Healthcare workers lack knowledge and skill in diagnosing mental illness, and public health facilities for the treatment of mental health problems (public health centers, hospitals, and the practice of general practitioners) are limited (Rudi, 2012). These limited services, coupled with low public awareness of both mental illness and treatment facilities, make it difficult for community members to access healthcare facilities. Therefore, families tend to bring patients to traditional healers, religious leaders, or to those involved with other types of alternative treatments. It has been argued, however, that the involvement of traditional healers constitutes the only feasible way of making mental healthcare available to the entire Indonesian population (Connor, 1982).

In Indonesia, the stigma of mental illness is widespread among society at large as well as among healthcare professionals. Seventy-five percent of mentally ill Indonesians have personally experienced stigma by the general public, government, healthcare workers, and through the media, all of which often portray them as violent, incompetent, and as objects of ridicule (Hawari, 2001). The breadth of stigma impacts mentally ill patients severely. Because the stigma of mental illness is rarely discussed openly, this produces misunderstanding, prejudice, confusion, and fear. Families and relatives often hide or ostracize the mentally ill because they are too embarrassed to bring them to a mental health care facility. Therefore, many patients are abandoned and neglected and become homeless. If

families do take their relatives to a psychiatric hospital, they rarely visit them. Those who were hospitalized who return home report having difficulty socializing with their family and friends or others in the community. For these reasons, many patients prefer to stay in the hospital forever (Hawari, 2001).

Patients experience both physical and psychological violence at the hands of family, staff, community, and government. Families and communities often practice *pasung* (restraint), meaning that patients are tied, chained, or handcuffed. They also practice *seklusi* (seclusion) by confining patients in small rooms or animal cages, or isolating them in the jungle. Some conditions are appalling – in some cases patients have only a hole in the floor for urine and feces (Hawari, 2001). These practices are carried out to control patients' violent behaviour or because their families and friends are ashamed of their mental illness. Psychologically violent behaviours include social isolation, abandonment, and blacklisting or labeling. Many patients are insulted, discredited, devalued, scorned, and shunned, leading to their rejection and ostracizing by their communities.

Patients are isolated by family members because they are believed to have a cursed illness, one that has been brought about by witchcraft. Demonic possession – the belief that sufferers of mental illness are possessed by demons, spirits, devils, ghosts, or have had a spell cast upon them by someone (Hawari, 2001) – is common among Indonesian cultures and religions. Traditional or alternative healers, referred to as “smart” people, are thus often the first choice for treatment by patients and their families and community members. *Kiyai* or *ulama*, chaplains, *dukuns* (shamans), paranormals, and Chinese healers are several types of smart people. However, during the treatment process of trying to remove the devil, Satan, or demons from the person's body, these traditional healers are often physically or

psychologically abusive of their patients (Hawari, 2001).

According to Hawari (2001), however, even patients who do receive treatment at a psychiatric hospital may experience violence from hospital staff. Nurses and security personnel sometimes restrain patients by tying or handcuffing them, and some patients are placed in a dark seclusion room. Even in hospitals, patients with a mental illness are often neglected, and hospital staff do not treat them with dignity or respect and fail to protect them (Amalia, 2010).

Erving Goffman (1963) reported on the patronizing attitude and moral superiority directed towards mentally ill patients in hospitals in the early 1960s. Mental health nurses can sometimes demonstrate a degree of stigma, with consequent abuse of patients and their families. But they are also often the objects of stigma themselves, which may help to deter patients and families from seeking the care they need. There is an assumption that working in a psychiatric hospital is risky, both because of the belief that mental illness is a contagious disease (Amalia, 2010) and the fear that nurses who work in a mental health area will face physical and psychological threats from their patients (Nursanti, 2006). Many non-psychiatric nurses also hold these beliefs, and make the assumption that mental illness is synonymous with being insane (Nursanti, 2006), leading to their viewing psychiatric or mental health nursing unfavorably (Izzudin, 2006).

Throughout my own career as a mental health nurse and educator, it has been clear that there are still many distortions and misconceptions of mental health nursing practice and mentally ill patients. For example, as a mental health nurse, I was surprised by how many people assumed that I had suffered an injury as a result of working in a mental health hospital. It is essential to understand the concept of stigma and mental illness and its effects,

and to develop interventions to guide practice, education, and research in mental health nursing.

1.2. Research Objectives

An intensive literature review reveals that very little is known about stigma and mental illness in Indonesia. Studies that examine stigma and mental illness among the Indonesian population have not addressed its impact on adults who experience concurrent stigma nor have they investigated the impact of stigma in mental illness on treatment utilization. My research investigates how mentally ill adults in Indonesia perceive mental illness and how they respond to stigmatization in their lives. In addition, it provides a more in-depth analysis to understand the relationships between stigmatization and mental illness and how they affect access to treatment. Equally important is an examination of the role and practice of Indonesian nurses in a psychiatric setting and how they understand mental illness. A further goal is to help inform mental health policies and regulations in the republic of Indonesia. A constructivist grounded theory (Charmaz, 2006) is used to understand the link between mental illness and stigma in Indonesia and to examine the influences of stigma on access to mental health services. The way that the research problem and questions are formulated in grounded theory reflects its methodological objective of explaining what is actually happening in practical life, rather than describing what should be going on (McCallin, 2003).

1.3. Research Questions

- a. How do mentally ill (adult) persons in Indonesia represent themselves and their illness?
- b. What is the mentally ill (adult) person's experience of stigmatization related to his/her condition?

- c. How does the mentally ill (adult) person respond to stigmatization on a daily basis?
What strategies are deployed to adapt to stigma?
- d. What are nurses' representations of mental illness?
- e. What are the social representations and responses to mental illness in Indonesian culture?

1.4. Theoretical Inspiration

The work of Link and Phelan (2001) provides theoretical inspiration in formulating a theory of stigma as it relates to mental illness. They conceptualize a framework that links four interrelated and co-concurrent components under the broad umbrella of stigma within a context of power. The four components are labeling, stereotyping, separation, and status loss and discrimination. In the first component (labeling), people distinguish between and label human differences such as skin color and sexual preference, differences that are currently awarded a high degree of social salience. Both the selection of salient characteristics and the creation of labels for them need to be understood as essential components of stigma. In the context of mental illness, labeling is the recognition that a person with a particular diagnosis differs from the norm in ways that have social significance. It is the assigning of negative attributions to these socially salient differences that leads to the perception that the differences are undesirable. In the second component (stereotyping), labeled differences are linked with dominant cultural beliefs or stereotypes. In this component, members of the dominant cultural group link labeled persons (e.g. the mentally ill) with certain undesirable attributes, which can be seen as undesirable either in the minds of others or among the labeled themselves. For example, it may be assumed that a person who has been hospitalized for mental illness represents a risk of violence. A third

component of the stigmatization process occurs when social labels denote a separation between “us” and “them.” Negatively labeled groups or individuals are placed in distinct and separate categories from the non-stigmatized. Separation occurs when the reactions of others to these differences leads to a pronounced sense of otherness (i.e., the individual’s personal awareness that others are treating him or her differently because of having a mental illness). In addition, when this separation is particularly thorough, members of a stigmatized mentally ill group may accept stereotypes about themselves as true and view themselves as fundamentally different from and inferior to other people (Link, Yang, Phelan and Collins, 2004). In the fourth component, status loss and discrimination occur when stigma interferes with an individual’s ability to participate fully in the social and economic life of his or her community. For example, when people or groups (e.g., mentally ill people) are labeled or linked to undesirable characteristics, a rationale is constructed for rejecting, stereotyping, and excluding this population. Finally, in Link and Phelan’s (2001) conceptualization, stigmatization is entirely contingent on a context of power, where access to social, economic and political power allows for the identification of difference, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. In the case of mental illness, those with power (e.g., mental health nurses) may label, stereotype, and cognitively separate themselves from groups with less power (e.g., mentally ill patients), alienating them from the rest of society at large.

CHAPTER 2

LITERATURE REVIEW

This chapter will provide a literature review of previous research related to stigma and mental illness. First, this chapter will describe mental health and mental illness as well as psychiatric or mental health facilities and treatments of mental illness in Indonesia. Then, it will discuss the concepts of violence and fear related to mental illness, along with the restrictive measures, including *pasung* (restraint) and *seklusi* (seclusion), that people with mental illness in Indonesia experience. In the last part of this chapter, stigma and the process of stigmatization among and towards the mentally ill in Indonesia will be discussed.

2.1. Mental Health and Mental Illness

Mental health, more than the mere lack of mental illness or mental disorder, is fundamental to better physical health status, enhanced productivity, improved quality of life, and improved interpersonal and social relationships. Mental health is an integral part of health and well-being, as reflected in the definition of health of the World Health Organization: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Mental health, like other aspects of health, can be affected by a range of socio-economic factors that need to be addressed through comprehensive strategies for promotion, prevention, treatment and recovery in a whole-of-government approach” (WHO, 2013, p.7). Mental health includes an individual's ability to enjoy life and create a balance between life activities and efforts to achieve psychological resilience. Mental health is the successful performance of mental functioning, resulting in the ability to adapt to change and to cope with adversity. Poor mental health hampers the ability of patients to realize their potential, work productively, and to contribute to their

community.

Understanding of mental health has changed over time across cultures and continents. There are some variations in the definition of mental illness, and in its assessment, classification, and standard guideline criteria that are widely used to understand mental health. Cultural differences, subjective assessments, and competing professional theories all affect how mental health is defined (WHO, 2001). A holistic model of mental health includes concepts of educational, anthropological, psychological, religious, sociological, and theoretical perspectives (Hattie, Myers and Sweeney, 2004; Witmer and Sweeney, 1992).

Mental illness is a clinically significant behavioural or psychological syndrome experienced by a person and marked by distress, disability, or the risk of suffering disability or loss of freedom (Varcarolis and Halter, 2009). In many cases, there appears to be a continuum between mental health and mental illness, making diagnoses complex (Hawari, 2001). Diagnosable mental disorders or health conditions are characterized by alterations in thinking, mood, or behaviour (or some combination thereof) associated with distress and/or impaired functioning (U.S. Department of Health and Human Services, 1999).

The term "mental illness" is used to denote a range of mental and behavioural disorders that fall within the International Statistical Classification of Diseases and Related Health Problems, Tenth revision (ICD-10) (WHO, 2013). These include “disorders that cause a high burden of disease such as depression, bipolar affective disorder, schizophrenia, anxiety disorders, dementia, substance use disorders, intellectual disabilities, and developmental and behavioural disorders with onset usually occurring in childhood and adolescence, including autism” (WHO, 2013 p.6). The Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-V) also defines different types of mental illnesses,

including those in the schizophrenia spectrum, anxiety and affective disorders, eating disorders, and personality disorders (APA, 2013).

Data from many studies indicate that mental illnesses are common around the world. Over a third of people in most countries report sufficient criteria to be diagnosed at some point in their life (WHO International Consortium in Psychiatric Epidemiology, 2000). According to Kessler et al. (2005), nearly half (45%) of those with any mental illnesses meet criteria for two or more disorders and the risk of mental illnesses is higher among the poor, homeless, the unemployed, people with low education, victims of violence, refugees, indigenous populations, children and adolescents, abused women, and the neglected elderly. By 2020, complications from mental illness will disable more people in the world than other health problems that arise from AIDS, heart disease, traffic accidents, and wars (Ravishankar, 2011).

Marginalization and deprivation can result in poor self-esteem, low self-confidence, reduced motivation, and feelings of hopelessness and isolation (WHO, 2010a). People with mental illnesses are less likely to receive treatment for their physical health conditions. For example, schizophrenic patients are 40% less likely to be hospitalized for ischemic heart disease, compared with people without mental illnesses who suffer from the same heart problem (Lawrence and Coghlan, 2002).

Mental illnesses also have an impact on family members, who may encounter difficult decisions about hospitalization, treatment, and housing. Sometimes they are afraid that they caused the illness, and the heavy demands of care may lead to burnout. Families also incur social costs from the emotional burden of looking after their members. Similarly, many health care providers experience a diminished quality of life, social exclusion,

stigmatization, and loss of future opportunities for self-improvement (WHO, 2003).

Erving Goffman (1961) in his book *Asylums* wrote a powerful indictment of total institutions and the abuses he believed that inmates suffered from conniving relatives, self-serving professionals, and poorly supervised custodial personnel. The terms mental illness and sickness were often placed in quotation marks in Goffman's work, communicating his disparaging attitude toward psychiatry and his skepticism about the professed goals of mental institutions. Goffman (1961) perceived mental illness as a social construct designating a spoiled identity that colluding others successfully imposed on a victim. "The mentally ill patients distinctly suffer not from mental illness, but from contingencies; the craziness or 'sick behaviour' claimed for the mental patient is by and large a product of the claimant's social distance from the situation that the patient is in, and is not primarily a product of mental illness" (Goffman 1961, p. 135). However, in his 1969 article, "The Insanity of Place," he changed his perspective somewhat, now believing that mental illness was indeed an illness from which patients suffered.

The WHO (2010a) stated that mentally ill people comprise a vulnerable group because they are:

- (1) subjected to high levels of stigma and discrimination; (2) experiencing high levels of physical and sexual abuse in a range of settings, including prisons and hospitals; (3) often encountering restrictions in the exercise of their political and civil rights; (4) not able to participate fully in their societies by taking part in public affairs, such as policy decision making processes; (5) not able to access essential health and social care (mostly in developing countries); (6) unable to access emergency relief services; (7) facing significant barriers in attending school and finding employment; and (8) much more likely to experience disability and die prematurely, compared with the general population (p.2-3).

All of these outcomes of mental illnesses have an impact not only on the patients themselves, but also on their families and society at large.

Mentally ill people experience high rates of mortality and disability. For example, a 2012 study revealed that every 40 seconds a person dies by suicide with an estimated 804,000 suicide deaths occurring worldwide, representing an annual global age-standardized suicide rate of 11.4 per 100,000 population (WHO, 2014b). The most common disorders among people who die by suicide are major depression and other mood disorders, schizophrenia, substance use disorders, and personality disorders (Bertolote and Fleischmann, 2002).

Around 30% of those suffering from a long-term physical health condition also have a mental illness (Barnett et al., 2012). Sufferers are at a higher risk of being overweight or obese (Kivimäki, et al., 2009). In the United States, people with severe mental illness die 25 years earlier than the general population on average (Torgovnick, 2008). In the UK, patients with mental illness are almost twice as likely to die from coronary heart disease than the general population, and four times more likely to die from respiratory disease (Phelan, Stradins and Morrison, 2001). Mental illnesses also increase the risk of infectious diseases (WHO, 2003). The mentally ill are at an increased risk of not complying with or sticking to medical regimens for other health conditions. The prejudice and discrimination that comprise the stigma of mental illness are important reasons for ineffective treatments and failure to seek care (Corrigan, Druss and Perlick, 2014).

Mental illness also has an economic impact on patients, families, and society with regard to both healthcare costs and individual productivity. For example, the WHO (2013) estimates that the cumulative global impact of mental disorders in terms of lost economic output will amount to US\$ 16.3 million between 2011 and 2030. Nicholl, Akhras, Diels and Schadrack (2010) indicate that there is a higher overall economic burden in the treatment of

recently diagnosed schizophrenia patients compared with chronic patients. According to Peele, Xu and Kupfer (2003), bipolar disorder has been deemed the most expensive behavioral healthcare diagnosis, costing more than twice as much as depression per affected individual. Total costs largely arise from indirect costs and are attributable to lost productivity (Laxman, Lovibond and Hassan, 2008).

A Canadian study showed that during a 30-day period, 8.4% of the working population will experience depression, anxiety, or a substance-related disorder (often alcohol related), or a combination of these (Dewa, Lesage, Goering and Caveen, 2004). The highest prevalence of anxiety disorders occurs among people in professional occupations (such as medicine or law) and high-level managers. The highest frequency of depression occurs among semi-professional workers (Dewa, et al., 2004). On the whole though, people with a mental illness disorder were significantly less likely to complete high school, enter college, or receive a college degree, compared to their peers without a mental illness (Kessler, Foster, Saunders and Stang, 1995). Mental disorders thus result in lowered productivity due to unemployment, or missed work or reduced productivity while at work.

The burden of caring for mentally ill patients often falls on families and relatives. Family members experience stress due to the emotional and physical challenges of caring for their member with mental illness (WHO, 2003). A lack of financial and medical resources only increases their difficulties and many cannot work at full capacity due to the demands of caring for patients (Seloilwe, 2006). Violence and incarceration among mentally ill people can also place a significant financial and social burden on communities. The prevalence of mental health problems is 'very high', especially among female inmates (van den Bergh, Gatherer, Fraser and Moller, 2011).

The mentally ill are vulnerable to low-quality care, abuse, and human rights violations, particularly in low-income areas with limited mental healthcare resources (WHO, 2003). Since they often lack the financial resources to maintain basic living standards, they are exposed to adverse living environments like slum areas or dwellings without sanitation or water. Studies have also found that a relationship exists between homelessness and mental illness, although as in the United States, homelessness may also reflect limited access to mental health services due to deinstitutionalization, which has resulted in limited availability of psychiatric mental hospital beds, and strict criteria for patients' hospitalization (Greenberg and Rosenheck, 2008).

2.2 Mental Health and Mental Illness in Indonesia

Indonesia is the largest archipelago in the world and is the 16th largest country in terms of land area at about 1,860, 360 sq. km (Biro Pusat Statistik Indonesia, 2012). The country consists of 33 provinces, each of which is sub-divided into districts (Kabupaten or Kota) with each district further divided into sub-districts (Kecamatan). Indonesia consists of approximately 17,000 islands located between Asia and Australia, although the five major islands are Sumatera, Java, Kalimantan, Sulawesi, and Papua, which borders with Papua New Guinea. Two remaining smaller groups of islands are the Maluku and Nusa Tenggara. More than 80% of Indonesia's territory is covered with water.

According to the Ministry of Health of Indonesia (2012), Indonesia is the world's fourth largest country in terms of population. Total population is 259,940,857, with approximately 118 million (52%) living in urban areas. The national average density is 109 people per sq. km but there are huge differences between the islands (Biro Pusat Statistik Indonesia, 2012). Around 60% of the population lives on Java Island, which is the densest at

951 people per sq. km., but which comprises only 7% of the country's total area; in contrast, the Island of Kalimantan has only 20 people per sq. km (Biro Pusat Statistik Indonesia, 2012).

Indonesian mental health services originated after the promulgation of a Mental Health Act under Dutch colonial rule in 1882 with the building of a hospital in Bogor, West Java province (Setyonegoro, 1976). Other hospitals followed in East, Central, and West Java, Sumatra, Kalimantan, and Sulawesi. All of these hospitals initially had a custodial style of caretaking and therapy that was used during the colonial period. Almost all of them were built on the periphery of towns and cities, but were gradually surrounded by new residential areas as a result of urbanization. A separate institution for long-term care patients was established in 1930 in Lenteng Agung, Jakarta. Most care was again largely custodial. Male patients undertook agricultural work, although physical and chemical restraint, as well as isolation were frequently used (Pols, 2006). Several physicians argued for the establishment of agricultural colonies devoted to long-term chronic patients not expected to improve, which would be run by male nurses (*mantris*) and local physicians (Kerkhoven, 1993).

When the Republic of Indonesia gained independence in 1945, there were four large psychiatric hospitals (each occupied by over 5000 patients) and 10 acute-care clinics. Due to overcrowding, they had also been functioning as custodial institutions. During the 1950s and early 1960s, Indonesian psychiatric hospitals continued to provide only custodial care; treatments such as occupational therapy and ECT were limited. Only those families who could afford it were able to purchase psychiatric medication (Kline, 1963). In 1961, the construction of the Dharmawangsa Sanatorium in South Jakarta, part of the first private mental health services in Indonesia, signaled psychiatric reform.

By 1966, the Mental Health Ministry was promoting the concepts of prevention, treatment, and rehabilitation as the basis of a comprehensive mental health care system. The number of hospitals devoted to the mentally ill in Indonesia doubled over the next decade and offered a variety of treatment methods. Legislation on mental health that was separate from the general health laws provided opportunities to expand the system of mental health care. With the development of out-patient services, the asylums became part of community mental health programs, offering consulting services to neighboring general hospitals as well as public health education. In 1993, separate mental health legislation was integrated into legislation on health in general, further supporting the integrated community approach adopted for mental health care three decades earlier (Pols, 2006).

In 2002, the central Indonesian government reorganized the health care system to promote a policy of decentralization. Mental health became a provincial responsibility when the Directorate of Mental Health became the Division of Community Mental Health under the Directorate of General Community Health. A period of decline for psychiatrists and nurses followed because of the underfunding of most psychiatric hospitals and the difficulty of integrating mental health into a general health program (Pols, 2006).

According to the Ministry of Health [MOH] of Indonesia (2013), the prevalence of severe mental disorders is 1.7 and mild mental disorder is about 60 per 1000 population. The most severely mentally ill people are in Jogjakarta, Aceh, South Sulawesi, Bali, and Central Java provinces. According to data from 33 psychiatric hospitals (RSJ) in Indonesia in 2012, the number of people with severe mental illness reached 2.5 million (Rudi, 2012). By region, the highest prevalence was found in Central Jakarta (22.8%), and the lowest in South Jakarta (10.9%) (Keliat, 2013).

In Central Java and Jogjakarta provinces, mental health problems are associated with the frequent incidence of earthquakes and eruptions from Mount Merapi. In Jogjakarta, which sees more mental disorders than the national average, 27 people, along with 1000 patients in the Central Java province, were released from pasung in 2012 and were taken to hospital (Keliat, 2013). In East Java, 558 cases of pasung were found and 42 post-pasung patients were treated in the Lawang psychiatric hospital until early 2013 (Keliat, 2013). In Nanggroe Aceh Darussalam (NAD) province, as many as 119 pasung cases were identified (Keliat et al., 2011).

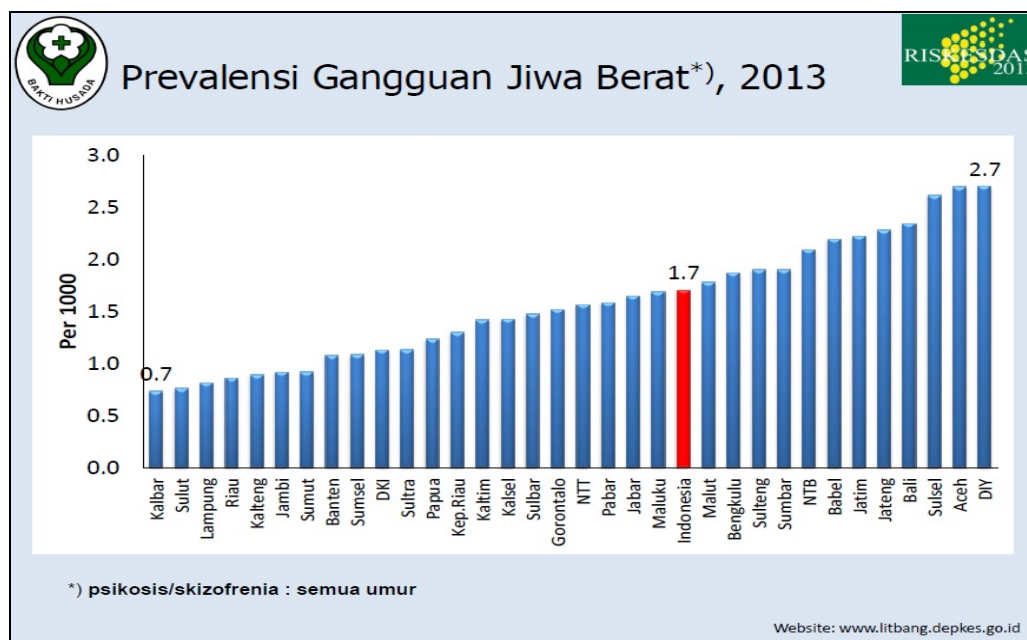
Treatment of mental illnesses in Indonesia is still not optimal. Less than 1% of Indonesia's total healthcare budget is directed towards mental health services, the lowest in Asia. Of the 334 health centers in Jakarta, only two have developed mental health services, making access to these services very limited. The country also has one of the lowest ratios of psychiatrists per capita in the world (Irmansyah, 2010), half of which confine their work to the capital city of Jakarta (Meshvara, 2002). According to the MOH of Indonesia (2013), a psychiatric consultation costs on average US\$25, not including drugs.

The country's decentralized health care system makes for uneven attention to mental health care across the country's 34 provinces. Some regional governments allocate little or no money to mental health care (IRIN, 2013). As much as 50% percent of the total population does not have health insurance (MOH, 2013). Only 6% of the population has access to ASKES (a government healthcare insurance), while 4% have social security. Private health insurance and health care benefits from companies amount to 1.7%. In Indonesia, the national and regional governments own most of the insurance plans; *Jamkesmas* or the national insurance plan makes up 28.9% and *Jamkesda*, or the local

provincial health insurance, 9.6% (MOH of Indonesia 2013).

Figure 2.1: Prevalence of Severe Mental Illness in Indonesia

(Source: MOH-RI, 2013)



Aceh province has the highest insurance coverage among all of the provinces, where only 3.4% of the population has no insurance. Jakarta province has the lowest health insurance coverage with 69.1% of the population without insurance (MOH, 2013). The government implemented new nationwide universal health coverage in 2014. Health Insurance (BPJS) is expected to start in 2015 and will cover most of the costs of mental illness.

According to Rudi (2012), barriers to accessing healthcare for mental health problems in Indonesia include limited physical access to healthcare facilities, public stigma against those with a mental illness, lack of public awareness and knowledge about mental illness, and low socioeconomic status. In addition, healthcare workers themselves lack knowledge

and skill in diagnosing mental illness. As a consequence, families bring patients to religious or other types of alternative healers for traditional treatments. It has been argued that the involvement of traditional healers constitutes the only feasible way of making mental healthcare available to the Indonesian population (Connor, 1982).

Currently Indonesia has 48 psychiatric hospitals and one substance abuse hospital, with 0.38 beds per 10,000 people and about 1 mental health nurse per 100,000 people (Kaligis, Amir and Diatri, 2011). According to the standards recommended by the WHO, Indonesia needs at least 80,000 beds for people with severe mental illnesses (Irmansyah, 2010). These hospitals are adequately equipped to treat mental patients, but in the future, patients will be encouraged to have treatment outside the hospital under the care of families and community caregivers (MOH, 2013). Mental health treatments are also based in the community on an outpatient basis, some of which are managed by nurses and doctors. However, these institutions or foundations are very limited at the present and only available in big cities such as Jakarta and Bogor.

A *Puskesmas* or public health center (PHC) is one community facility providing services for patients with mental illness who reside in the *Kelurahan* (neighborhood). They offer diagnosis, basic medical treatment, mental health nursing care, laboratory services, and a counseling and referral system. All Puskesmas are managed by the Ministry of Health of Indonesia (Broto et al., 2009); they are advertised as providing a comprehensive, integrated, equitable, acceptable and affordable service in the community with a focus on prevention and rehabilitation.

Another facility for outpatients is the *Posyandu* or Integrated Health Care (IHC). It is a basic community health activity organized by and for the people assisted by healthcare

workers and community health teams. IHC is a self-help activity in the field of public health with the person in charge of the village promoting the integration of services between the community, the Puskesmas and the hospitals.

There is also a community nursing program called Community Mental Health Nursing (CMHN). The first CMHN was opened in Banda Aceh in 2005 after the tsunami disaster to improve the ability of nurses in public health centers to provide community mental health services. The CMHN program has successfully treated mentally ill patients who were on *pasung* in Aceh after the tsunami (Keliat, 2013). CMHN is a problem-solving service that can be directly accessed by the public because the nurses go directly into the community to reach out to patients and their families. It is a comprehensive, holistic, community psychiatric nursing service that focuses on healthy people, those who are at risk of developing a mental disorder, as well as sufferers, to help them be independent and productive (Keliat, et al, 2011). The goal of the CMHN service includes providing outpatient psychiatric treatment services, which include supported housing with full or partial supervision, local primary care medical services, Puskesmas, and Posyandu.

The CMHN program in Indonesia recruits health centre nurses (Keliat and Akemat, 2004) to provide them with a basic course in Community Mental Health Nursing to enhance their knowledge and skills so they have the competence to carry out the nursing care of mentally ill patients and to aid nurses in implementing and supervising activities in the community (Azizah, 2011; Keliat et al, 2011; Kusumawati and Hartono, 2010). The CMHN consists of community mental health nurses who also have had assertive community training (ACT) (Keliat, et al, 2011; Keliat and Akemat, 2004). ACT is an intensive and highly integrated approach for community mental health service delivery (Dixon, 2000). The ACT

program is a model of mental health services delivery that provides comprehensive, individualized care (Keliat et al., 2011). The WHO was positive about the implementation of the CMHN program in Banda Aceh, Indonesia, because it could help meet the goal of addressing mental health issues in the community (Keliat, et al., 2011).

Demonic or spirit possession and mental illness

Many theorists have tried to explain the root causes of mental illness and one of these theories is related to demonic possession. Demons or spirits are believed to attach themselves to people and make them poor-spirited or mad. Possession may be considered voluntary or involuntary and may be considered to have beneficial or detrimental effects to the patient. Demons are able to ‘demonically possess’ people without the victim’s knowledge or consent, leaving them morally blameless (Amorth, 1999). The belief that one is possessed by spirits is more common among women than men (Kehoe and Giletti, 1981).

Although demonic possession is not a valid psychiatric or medical diagnosis recognized by the DSM-V or the ICD-10, many cultures and religions, including Islam, Christianity, Buddhism, Haitian Voodoo, and Hinduism retain some sort of belief in the ability of demons or spirits to take control of a human body. In Islam, for example, it is possible for *jinn* to possess humans. Allah says in the Quran (Interpretation of the meaning): “Those who eat Ribaa [usury] will not stand (on the Day of Resurrection) except like the standing of a person beaten by Shaytaan (Satan) leading him to insanity” (Quran 2:275). If a person who has this sickness is rational, he will be brought to account for his words and actions. But if this sickness has overwhelmed him to the point that he has lost his mind and free will, then he is like one who is insane and is not accountable. Hence in Arabic the word *mass* (possession) is used to refer to *junoon* (insanity) (Lisaan al-Arab 6/217). Some

Christians also hold that demonic possession derives from the Devil, i.e. Satan, or other demons. Many still believe that demons really do exist as actual spiritual entities, and that they can adversely affect or invade the lives of individuals. In many Christian belief systems, Satan and demons are fallen angels (MacKenzie, 1999).

Alternative/Traditional Treatments of Mental Illness in Indonesia

The use of traditional treatments in Indonesia began centuries ago, and many mentally ill patients and their families continue to seek treatment from traditional or alternative healers (Hawari, 2001). Those providing alternative and traditional treatments are key persons for people who have mental health problems (Hirokoshi, 1980; Lukens-Bull, 2005; Salan and Maretzki, 1983). However, only limited studies on the benefits of these traditional treatments and religious healers have been undertaken.

Healthcare professionals are often tolerant of traditional treatments and believe that religious beliefs, spiritual ideas, and modern medicine each play a role (Good and Subandi, 2004). Many Indonesians attribute mental illnesses to the influence of supernatural ancestors or to bewitchment, and they perceive that traditional treatments can help. Some traditional beliefs dictate that good health consists of a harmonious balance between hot and cold substances in the body and or that mental disorders imply a disturbance between the soul and the flesh. A study conducted by Hirokoshi (1980) investigated the practices at an Islamic *asrama* (boarding school) in West Java, where people with mental illness were placed under the guidance of a religious teacher. The study found that Islamic leaders played an important role in the treatment of mental illness.

Traditional or alternative healers are called smart people. Traditional or alternative Indonesian treatments are divided into four categories: healers who use traditional herbs

such as *jamu* or herbal drinks, food, water, and oil; traditional instruments (coins or glass); traditional methods (massage, acupressure, etc.); and healers who use supernatural powers (energy or aura) (Salan and Maretzki, 1983). There are about 500,000 traditional healers throughout Indonesia (MOH, 2013).

One place to have alternative treatments is at a *Pesantren* or *Pondok Pesantren* (Islamic boarding schools). “The term pesantren derives from the root word santri or student - pe-santri-an or the place of the santri” (Lukens-Bull, 2005, p.48). Pesantren have played a major role in offering healing or treatment based on Islamic values. Islamic scholars or teachers (*kiyai* or *ulama*) work in the Pesantren. The word ‘kiyai’ is of Javanese origin. Dhofier (1980) mentions that Indonesians refer to kiyai as ulama, which is the plural form of the Arabic word *alim* (knowledgeable person). The Pesantren is a large boarding school that will have several kiyai living and teaching there (Dhofier, 1980). Many Indonesian Muslims consider a kiyai to be higher ranked than an *ustadz* because a kiyai runs his own boarding school and has mystical abilities (Lukens-Bull, 2005). “A kiyai has his position and authority because people will listen to what he says” (Platvoet and van der Toorn, 1995, p. 261).

Chaplains, serving a Christian institution, are another form of smart people. They are priests, pastors, or lay representatives of a religious tradition, attached to a private chapel. A chaplain provides spiritual and emotional support for service personnel in schools or universities, prisons, and healthcare settings (Hewson, 2012; Norman, 2004).

People who are suffering from mental illness are also brought to *dukuns*. A dukun is an Indonesian term for shaman (Echols and Shadily 1992; Harvey and Wallis, 2007). In Indonesian society, dukuns are traditional healers, spirit mediums, custom and tradition experts, and on occasion, sorcerers and masters of black magic. Indonesian people have

always believed in supernatural things such as ghosts, spirits and witchcraft. A dukun is believed to be able to communicate with malevolent and benevolent spirits.

Paranormals are also chosen as alternative healers by patients, families and community members. Some paranormal beliefs include those that pertain to ghosts, extraterrestrial life, and extrasensory perception and cryptids (Stuart, 1993). Only limited studies have focused on examining the results of paranormal practices and no experimental results have gained wide acceptance in the scientific community as valid evidence of the paranormal (Oling-Smee, 2007).

Many mentally ill people and their families also use Traditional Chinese Medicine (TCM) as a treatment option. TCM is widely used in China and in the West. TCM practices in Indonesian society include various forms of herbal medicine, acupuncture, massage, and dietary therapy. However, the effectiveness of Chinese herbal medicine remains poorly researched and documented (Shang et al., 2007). Since 2003, there have been specific rules governing the practice of traditional medicine including that provided by paranormals and TCM practices in Indonesia. This rule was made by the MOH of Indonesia Number 1076/Menkes / SK / VII / 2003 (MOH, 2003).

2.3 Violence and Mental Illness

Violence is one of the most serious consequences of mental illnesses. Violence is “ the intentional use of physical force or power, threatened or actual, against oneself, another person or against a group or community that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation” (Krug et al., 2002, p.6). Violence among people with a mental illness is 2.5 times greater than among those of a comparable demographic population (Arseneault et al., 2000; Corrigan and

Watson, 2005). It directly and indirectly affects the quality of life of patients, their families, the community, and mental health professionals. Violence is a major professional issue in both inpatient and outpatient facilities

Self-directed violence (suicide)

Self-directed violence or suicide is an important public health problem because it is one of the leading causes of death worldwide. The WHO (1999) has estimated that around the world, one suicide occurs approximately every minute and one suicide attempt approximately every three seconds and more people die from suicide than from armed conflict. Among 15-44 year olds, self-injuries are the fourth leading cause of death and the sixth leading cause of disability (WHO, 2002a). By 2020, suicide will be the 10th most important cause of death worldwide (Murray and Lopez, 1997). Research has indicated that about 4% of people report lifetime suicidal ideation, 1% have a suicide plan or ideation, and 0.5% have attempted suicide worldwide (Borges et al., 2006; Crosby et al., 2011).

Mental illnesses are a major risk factor for suicide (Keliat, 1991; WHO, 2002a), with more than 90% of victims of suicide having a diagnosable mental illness (Mann, 2002). Several types of mental disorders that have been linked to suicide include depression, substance abuse, anxiety disorders, personality disorders, and schizophrenia. Co-occurring conditions are particularly common among those who commit suicide. For example, depression combined with alcohol abuse occurs in 80-90% of those who commit suicide (Yip et al., 2012).

Violence toward People with Mental Illness

Many studies have found that people with mental illness experience physical, sexual, and psychological violence (McFarlane, Schrader and Bookless, 2004) and the consequences

of this victimization can be serious in terms of relapse of mental illness (Lam and Rosenheck, 1998). In developed countries researchers indicate that the rates of victimization of mentally ill people are higher than the general population. For example, Schomerus et al., (2008) analysed data from the European Schizophrenia Cohort (EuroSC) with a 2-year follow-up study of 1208 patients in the UK, France, and Germany, and they found that 10% of patients were victims of violent crimes and 19% of non-violent crimes. In another study in Finland, violent victimization of deinstitutionalized patients with schizophrenia was found to be 5.6% during a three-year follow-up period, 3.3 times higher than the general population (Maniglio, 2009). In the UK, a comparison between psychotic inpatients and outpatients living in an inner-city area indicated that violent victimization rates of the outpatients were double that recorded in the general population (Walsh, Buchanan and Fahy, 2002).

In Australia, 88% of those admitted to a psychiatric hospital have experienced victimization at some point in their lives, with 84% having been physically assaulted, and 57% enduring a sexual assault (McFarlane, Schrader and Bookless, 2004). Patients who become the victims of crime are more often hospitalized and remain hospitalized for longer periods of time (Hawari, 2001; Neria, Bromet, Carlson and Naz, 2005). Solomon, Cavanaugh and Gelles (2005) indicate that violence often takes place in a family setting rather than between strangers. Schizophrenic patients are the recipients of an especially high frequency of assaults from family members (Cascadi, Mueser, DeGiralomo and Murrin, 1996; Keliat, 1996).

Violence Perpetrated by Mentally Ill People

Swanson et al. (2002) found that the risk of violence among persons with serious mental illness is a significant problem and it is substantially higher than estimates of the

violence rate for the general population. People with mental illness most often direct their violence at people they know, rather than strangers, which is the same pattern seen in the general public (Estroff, Zimmer, Lachiotte and Benoit, 1994; Lefley, 1997). The most likely targets of violence are family members or friends (87%), and the violence typically occurs in the home (Monahan et al., 2001).

There is increasing concern about the level of violence within mental healthcare settings because of patients' violence (Davison, 2005; Elliott, 1997; Farrell, 1997; Keliat, 2002). More assaults occur in healthcare and social service industries than in any other area, including law enforcement (Love and Morrison, 2003). There is some evidence that assault rates in hospitals reflect the level of violence in the population they serve (Farrell, 1999; Walker and Caplan, 1993). For example, "patients may be at increased risk for conducting violence because of socioeconomic factors and because of how, where and with whom they live, rather than because of their illness" (Estroff et al., 1994, p.670). In health facilities, some social-environmental factors seem particularly influential: the physical facilities provided for patients, visitors and staff; the experience, training, supervision and numbers of staff; and the policies in place to manage the clinical environment (Royal College of Psychiatrists, 1998). The rates of violence are highest in psychiatric intensive care units, forensic units, and locked wards (Davison, 2005).

Patient violence in the workplace continues to be under-reported (Farrell, Bobrowski and Bobrowski, 2006; Lanza, 2006). In the United States, one study demonstrated that mental health professionals have a 5 to 48% chance of experiencing a physical assault by a patient during their career (Erdos and Hughews, 2001). Nurses from several different types of units are at risk of becoming victims of violence (Anderson, 2002; Holmes et al., 2012;

Holmes, Kennedy and Perron, 2004; Lawoko, Soares and Nolan, 2004) and they are believed to be 16 times more likely to experience violence from patients than any other worker (Elliot, 1997). Many have indicated that they have experienced both verbal and physical assaults over their careers (Hesketh, et al., 2002). According to Holmes (2005) and Holmes and Federman (2003), nursing practice cannot adhere to nursing ideals in an environment where security prevails and where the population being cared for is at risk of violence.

2.4 Fear and Mental Illness

Many studies reported that the violence or potential for violence from patients produces fear in family and community members. Gower (2004) states that fear is an unpleasant emotion caused by the belief that someone or something is dangerous, likely to cause pain, or a threat. When people feel threatened, they will most likely generate negative emotions.

Fear of Patients with Mental Illness

Studies indicate that people with a mental illness generate the fear that they may be violent. According to Lamb (1999), the major cause of stigma is the perception that people with mental illnesses are dangerous. For example, they are often described as ‘lunatics,’ or as a ‘mad person’ (Tudor, 1996), or as ‘schizos, nutters, psychos, fiends, monsters or maniacs’. Corrigan et al. (2001) proposed that fear of those with a mental illness leads to distancing from the rest of society, and the resultant social exclusion has an adverse effect on life opportunities (Sayce, 1998). The majority of Americans believe that persons with mental illnesses pose a threat towards themselves and others (Pescosolido et al., 1999). One study demonstrated that 38% of the people surveyed agreed that those with a mental illness were more dangerous than the rest of society (Fraser, 1994).

Healthcare professionals' fears are derived from perceptions about dangerousness and violence. Nurses who work with the mentally ill as well as those who do not, much like the general population, can perceive patients as dangerous and fear their violence. Their fear is often caused by previously experienced physical assaults and the physical size of patients. As some scholars have pointed out, nurses' experience of a variety of emotions, such as fear and repulsion, can influence the nurse-patient relationship (Holmes and Federman, 2003; Holmes, Perron and O'Byrne, 2006; Kindy, Petersen and Pakhurst, 2005). These sensations may alter the perception of risk and the way to address it. Staff may engage in restrictive interventions as a means of neutralizing the risk of being violated (Holmes, Perron and Guimond, 2007). Patients who evoke feelings of fear are also likely to be treated with less trust and less commitment, or neglected altogether (Whittington and Balsamo, 1998).

Fear Experienced by People with Mental Illness

A major source of fear of people with mental illnesses is their perceptions about their mostly negative experiences of treatment in the mental health care system (Keating and Robertson, 2004). Concerns about the unpredictable nature of their illness, loss of control, and the overall impact on their quality of life are further sources of fear for patients. They may be worrying about their ability to manage their personal, social, or financial affairs. They may be lonely because they may be afraid to make and maintain relationships with others, and they fear the lack of adequate support to help them reintegrate into society (Keating and Robertson, 2004).

Fear causes an interrelationship between nurses and patients, as both are objects and subjects of power (Holmes, 2005; Holmes and Federman, 2003). Fear plays an important

role in affecting how nurses interact with patients (Farrell, Bobrowski and Bobrowski, 2006; Holmes, Perron and O'Byrne, 2006). Whittington and Balsamo (1998) state that if fear and the need for personal safety become an integral parts of nurses' interactions and interventions with their patients, patients may become distanced from their caregivers.

Media and Fear of Mental Illness

Research on patients and the population of ex-psychiatric patients highlights public fears of dangerousness. A common theme is the public's understandings of mental illness, based on what they have learned through the years from watching television shows and other media (Wahl, 2003). For example, it was reported that 89% of respondents in one study watched television shows and reported being concerned that the people with mental illnesses were portrayed as being violent, dangerous, different, and laughable (Wahl et al., 1999). Two studies found that 75% of stories dealing with mental illness focused on violence (Phelan and Link, 2004), and that 72% of characters portraying mentally ill people were presented as dangerous (Stout, Villegas and Jennings, 2004). In addition, one U.S. study using university volunteers demonstrated that reading a newspaper reporting a violent crime committed by a mentally ill patient led to increased negative attitudes toward people with mental illnesses (Thornton and Wahl, 1996).

2.5 Restrictive Measures and Mental Illness

Prevention and management strategies for dealing with the potential for violence among the mentally ill concerns families, communities, and those working in mental health treatment centres. Protective restrictive measures continue to be used in all of these settings. For example, physical restraint by families of people with a mental illness is known to occur in many parts of the world, although it has attracted limited investigation (Minas and Diatri,

2008). Physical restraint (or pasung), in particular, is a measure still used in Indonesia (Broch, 2001; Minas and Diatri, 2008), and is often carried out by community members to protect others or to prevent patients from wandering the streets (Keliat et al., 2011).

Physical restraint can have significant risks; therefore, seclusion might be preferable in some circumstances. A study in Aceh province, Indonesia, indicates that patients who are restrained by their families for more than 20 years will experience muscle atrophy, making them unable to walk (Puteh, Marthoenis and Minas, 2011). Physical restraint can sometimes be associated with sudden death (O'Halloran and Frank, 2000).

Healthcare professionals are often confronted with the decision about whether or not to use restrictive measures. Seclusion can be used for the management of violent behaviour that jeopardizes the immediate physical safety of the patient, a staff member, or others (US Centers for Medicare and Medicaid Services Department of Health and Human Services (CMMS-DHHS), 2006). It essentially involves moving patients to an environment where they can be more safely managed (Keliat, 2013). Patients can be placed alone in a room or in an area where they are physically prevented from leaving (CMMS-DHHS, 2006; Keliat et al., 2011). Physical restraint should only be used as a last resort and people performing it must be well trained to prevent injury to themselves and particularly to the patients. According to CMMS-DHHS (2006), restraints do not include devices such as orthopedically prescribed devices, surgical dressings or bandages, or protective helmets to permit the patient to participate in activities without the risk of physical harm, or other methods that involve the physical holding of a patient for the purpose of conducting routine physical examination or tests or protecting the patient from falling out of bed.

There are significant humanitarian, ethical, and legal issues associated with the use of restraint and seclusion (Holmes, Perron and Guimond, 2007; Sailas and Wahlbeck, 2005). Decisions regarding the choice of seclusion and restraint in a threatening situation will most often be influenced by colleagues, and are culturally reinforced by the institution (Holmes, Perron and Guimond, 2007). Keating and Robertson (2004) point out that when patients are perceived as dangerous, aggressive, or difficult to manage, staff may employ restraint and seclusion in a rather arbitrary fashion. Their apprehension about being victimized may motivate them to manage aggressive incidents with physical methods on a frequent basis (Foster, Bowers and Nijman, 2007). Ideally, restraint and seclusion should only be used as a last resort because each of these interventions can have potentially fatal complications of psychiatric patients. However, avoiding these interventions altogether is not an option if serious injury to self and/or others is to be prevented. In addition, restraint should be used with consideration for the self-respect, dignity, privacy, cultural, and special needs of the patient (Royal College of Psychiatrists, 1998).

Both restraint and seclusion have negative impacts for patients, healthcare professionals, and for others who provide these treatments. Restraints pose a major safety risk to both patient and hospital staff, both of whom may be injured when trying to put them on. Restraint and seclusion can also cause physical and psychological trauma, leading some patients to commit suicide (Haimowits, Urff and Huckshorn, 2006). Some nurses are uncomfortable with the dilemma of using these measures, and unclear rules about their application can make them anxious, afraid, or angry (De Benedictis, et al, 2011; Sequeira and Halstead, 2004). They may become skeptical about what to do with violent patients (Kontio et al., 2010).

Pasung (Restraint) and Seklusi (Seclusion) for People with Mental Illness In Indonesia

Some Indonesian studies have found that both pasung and seklusi are commonly used against those suffering from a mental illness. According to Keliat (2013), nearly 0.5% of Indonesians (more than 1 million people) suffer from a severe mental disorder, many of which go untreated due to the lack of professional mental health care in many provinces. This in turn results in many of the mentally ill people being put on pasung by others (Lestari and Wardhani, 2014; Minas and Diatri, 2008; Ministry of Health of Indonesia, 2013).

Although pasung is used on mentally ill people by their families and communities, it can also be used by healthcare professionals in hospitals. It refers to both physical and chemical restraints but it also encompasses forms of seclusion. Patients can be put into shackles, tied to pillars, chained, handcuffed, or put in *balok* [wooden stocks] (Hawari, 2001). They can also be locked in rooms or confined in a shed or animal pen (Maramis, 2007). In some villages, mentally ill people are typically chained behind or inside their homes. As methods of control, both measures pose obvious physical and emotional risks to patients (Daulima, 2014; Keliat et al., 2011).

Family and community members place patients in pasung because they are ashamed of their mentally ill relatives or else they fear they will be violent either to themselves or to others (Keliat et al., 2011; Minas and Diatri, 2008). Limited mental health facilities in the community only add to the pressure to initiate such inhumane treatment (Daulima, 2014; Doloksaribu, 2008). Although it may look as if families are unfeeling in their adoption of pasung, studies have found that the procedure often causes conflict among family members. In one study it was found that the family was helpless against the demands of the surrounding community who felt threatened by the behaviour of the sufferer (Lestari and

Wardhani, 2014). Other family members did not want to do pasung because they pitied their relative, but the psychological pressure from those around them forced them into it (Keliat et al., 2011; Daulima, 2014). It appears that the decision-making process on pasung is a dilemma for many families (Daulima, 2014). More in-depth studies are needed to examine the problems faced by the families of people with mental illness who do pasung (Wardhani et al., 2011).

Pasung has recently become the biggest mental health issue in Indonesia. Keliat (2013) determines that 18,800 (0.18%) Indonesians are still under pasung to prevent them from attacking other people. In rural areas, 18.2 percent of people with a mental illness are under pasung, while in the urban areas 10.7% of mentally ill people have been restrained in this way (Ministry of Health of Indonesia, 2013). In 2011, the government of Indonesia launched the '*Bebas Pasung*' (Free Pasung) Program but it has not worked well so far because of a lack of funding and a limited number of trained or educated healthcare professionals to run it. It is estimated that only about 3,500 patients have been released from their pasung (Keliat, 2013).

2.6 Stigma and Stigmatization

The word "stigma" in ancient Greek and Roman societies described marks that were tattooed or burned into the flesh of criminals or slaves, a visible testament to their marginal social status or deviance (Jones, 1987). The word for prick was "stig" and the resulting mark became "stigma" (Falk, 2001). Webster's *New Twentieth Century Dictionary* (1983) defines stigma as "something that detracts from the character or reputation of a person, group, etc.; a mark of disgrace or reproach; a mark, sign, etc. indicating that something is not considered normal or standard." Stigma is a socio-cultural process by which members of marginalized

groups are labeled by other people as abnormal, shameful, or otherwise undesirable. Its association with mental illnesses is a worldwide problem.

Today, the concept of stigma is defined by sociologists, psychologists, and psychiatrists. Scholars from different disciplines have developed various concepts of stigma, two of which seem particularly prominent. First, the concept of stigma has been applied to an array of unique circumstances, leading scholars to conceptualize stigma in somewhat different ways. Second, research on stigma is clearly multidisciplinary (Link and Phelan, 2001) and represents a complex interaction among social science, politics, history, psychology, medicine, and anthropology (Smith, 2002; Stafford and Scott, 1986). For example, stigma has been studied extensively by many disciplines, including nursing (e.g., Doyle and Cruickshank, 2012; Gary, 2005), medicine (e.g., Wallace, 2012), psychology (e.g., Corrigan and Watson, 2002), sociology (e.g., Goffman, 1963; Link and Phelan, 2001), anthropology (e.g., Kleinman and Hall-Clifford, 2009), history (e.g., Guy, 1998), economics (e.g., Moffitt, 1983), and social work (e.g., Ahmedani, 2011; Matsuoka and Thompson, 2009).

Erving Goffman, in his book *Stigma: Notes on the Management of Spoiled Identity* (1963), is credited with the first notable modern use of the term and with providing the most established definition. He adopted the term stigma to represent perceived immoral status – a token of shame or disgrace that publicly marked people to be avoided. Arguing that stigma “is really a relationship between an attribute and stereotype” (p. 4), he defined stigma as an “attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one.” A person’s stigma “makes him different from others in the category of persons available for him to be and of a less desirable kind.” Thus, the

stigmatized are perceived as having a “spoiled identity” (p. 3). Since the “normal group,” defined as those who fit societies’ expectations of a “normal identity,” perceives the stigmatized as inferior, the person with stigma is thus seen as “not quite human” (p.15). Stigma thus separates people from one another based on a socially conferred judgment that some persons or groups are tainted and “less than” (Goffman, 1963 p. 2-3.).

Stigma can be seen as a relationship between an attribute and a stereotype which produces a definition of stigma as a "mark" (attribute) that links a person to undesirable characteristics (stereotypes). Goffman (1963) identified three types of stigma: (1) abominations of the body (e.g. physical deformities); (2) blemishes of individual character (e.g. mental health problems, unemployment, and crime); and (3) tribal stigma or tribal identities (e.g., race, religion, etc.) Stigma then becomes the negative evaluation of a person as tainted or discredited on the basis of attributes such as mental illness, ethnicity, drug misuse, or physical disability (1963).

Goffman’s book generated a profusion of research on stigma and many of his ideas on stigma have been carried forward in more work on its conceptualization. Most authors have agreed with the basics of Goffman’s definition. For example, Stafford and Scott (1986) define stigma as a characteristic that goes against the expectations of people to behave in a certain way at a certain time. Stone, Stone and Dipboye (1992) see stigma as the perception of aberrant or atypical attributes when contrasted with social expectations for typical (or “normal”) people in a particular context. Jones et al. (1984) break the concept of stigma down into six dimensions: "concealability or how obvious the characteristic is to others; course or whether the stigmatizing condition is reversible over time; disruptiveness or the extent to which a mark strains or obstructs interpersonal interactions; aesthetics or the extent

to which a mark elicits a reaction of disgust; origin or how the condition came into being; and peril, referring to feelings of danger or threat that the mark induces in others. Stigmatizing 'marks' become associated with 'discrediting dispositions' or negative evaluations and stereotypes" (Jones et al., 1984, p.158).

Crocker, Major and Steele (1998) redefine Goffman's definition, noting that stigmatized characteristics convey "a social identity that is devalued in a particular social context" (p. 505). This definition highlights two important properties of stigma. The first is that the stigmatized characteristic assumes a meaning beyond the characteristic and reflects the person him or herself. The second is that characteristics produce stigma not through their own inherent properties but through their context-specific symbolic value.

Link and Phelan (2001) define stigma in terms of the interactions among labeling, stereotyping, separation, status loss and discrimination. According to them, stigma is produced through the recognition of difference (labeling) and the belief that this difference has negative social connotations (stereotyping). Separation occurs when people realize their "otherness" ("felt stigma"), which prevents them from participating fully in society and leads to their exclusion (discrimination). Corrigan and Rusch (2002) similarly conceptualized stigma as having three "component social cognitive structures," wherein dominant social groups hold negative beliefs or stereotype a minority group, where the dominant group's negative emotional reaction to the stereotype leads to prejudice, and where discriminatory behaviour towards the minority group is motivated by that prejudice. Most recently, Hannem and Bruckert (2012) recognize that discrimination, marginality, and social injustice are enmeshed within the concept of stigma. They argue that the perpetuation of stigmatizing attitudes is linked to contemporary notions of risk, riskiness, and danger when 'deviant'

populations are so labelled in the name of social control and risk management. Green et al. (2005) contend that there is most likely a power differential favoring those without the characteristic over those who have it. Thus, they see the stigmatization of people with a specific illness or condition as a complex process involving the labeling of difference, the negative evaluation of that difference by others, and the negative social and emotional outcomes for the affected individual.

Corrigan and Watson (2002) and Corrigan and Kleinlein (2005) define two levels of stigma: public stigma and self-stigma. Public stigma occurs when large social groups endorse and act on stereotypes held against a stigmatized group, such as people with a mental illness. Goffman introduced the idea of "courtesy stigma" to refer to the stigma that attaches to those who are associated with a stigmatized person. As others have noted, stigma has a wide impact, affecting more than those directly stigmatized, like family and friends (Lefley, 1997; Phelan, Bromet and Link, 1998), and mental healthcare providers or support groups (Dichter, 1992; Persaud, 2000).

Corrigan and Kleinlein (2005) point out that both public and self-stigma include stereotyping, prejudice, and discrimination. In public stigma, negative beliefs or stereotyping of a group are related to ideas of danger, incompetence, and character weaknesses. Prejudice, or the agreement with these beliefs, produces anger and fear that leads to the discriminatory response of, for example, providing little support for work or housing opportunities. Regarding self-stigma, stereotyping is based on perceptions of character weaknesses and incompetence; prejudice is related to the stigmatized individual's agreement with these perceptions, leading to low self-esteem, and thus discrimination. In addition, the behavioural response to prejudice leads to the failure of mentally ill persons to pursue work

and housing opportunities. A diagnosis of a mental illness can thus be understood as a combination of problems of knowledge (ignorance), attitudes (prejudice), and behaviour (discrimination) (Thornicroft, Brohan Kassam and Lewis-Holmes, 2008).

Ahmedani (2011) defines three specific levels of stigma: self, social, and professional. Self-stigma he defines as stigma internalized by an individual, which results in low self-confidence and self-esteem that may lead to altered behaviour. Social or public stigma results from a society's endorsement of a particular stereotype, which leads to prejudice and discrimination against, for example, those with a mental illness, and can influence a person to feel guilty and inadequate about his or her condition. Ahmedani's third level of stigma is the stigma held by healthcare professionals, and many studies are now beginning to recognize the impact of this kind of stigma (Nordt, Rössler and Lauber, 2006; Volmer, Mäesalu and Bell, 2008; Tsao, Tummala and Roberts, 2008; Sriram and Jabbarpour, 2005; Uçok et al., 2004). Stigma held by health professionals may develop very much in the same way as social or public stigma. For example, pharmacy students who desire more social distance from people with schizophrenia are also less willing to provide counselling for medication (Volmer, Maesalu and Bell, 2008). A study with Swiss nurses, psychiatrists, and psychologists found that their desire for social distance from people with mental illnesses was similar to the general public's (Nordt, Rössler and Lauber, 2006). Patients have also reported labeling and marginalizing by health professionals (Liggins and Hatcher, 2005). Some patients have complained of different and unequal access to treatment as compared with people without a mental illness (Desai et al., 2002). Other authors have noted that healthcare professionals may not be as attentive to or do not provide as many community referral options for people with mental illness (Gassman, Demone and Albilal, 2001).

Patients who are disenchanted by the treatment process may end treatment early or fail to seek it in the future, creating a barrier to their well-being or even to their acknowledgement of their disease.

In summary, one of the curious features in the literature concerning stigma is the variability that exists in the definition of the concept. It is clear that most definitions of stigma are developed from Goffman's 1963 book *Stigma: Notes on the Management of Spoiled Identity*. His observation that stigma can be seen as the relationship between an attribute and a stereotype is an important precedent. Cultural value systems that differ over time determine and influence the definition of stigma. For example, normal and abnormal, heterosexual and homosexual, or white and non-white are largely determined by social and cultural attitudes of acceptance or ostracism regarding particular categories of people. In addition, the fact that stigma is studied and explored from multiple disciplines works against a universal definition of stigma. Nonetheless, although stigma is defined in different ways, its definitions contain fundamental similarities. They are mainly conceptualized as a construct manifested in negative attitudes, behaviours, and feelings toward stigmatized people or groups. Most definitions also involve elements such as labeling, stereotyping, social isolation, prejudice, rejection, ignorance, status loss, low self-esteem, low self-efficacy, marginalization, and discrimination.

Mental Health Stigma among People in Indonesia

Many studies demonstrate that stigma in Indonesia is a major problem and one that is experienced by patients and families in their communities, as well as by healthcare professionals. According to Hawari (2001), it is estimated that 75% of people with mental illness feel that they have been stigmatized by government, healthcare workers, the media,

and the general public. Because of stigma, mental illness is rarely discussed openly and produces misunderstanding, prejudice, confusion, and fear (Lestari and Wardhani, 2014). Mentally ill people, especially those diagnosed with schizophrenia, are often treated inappropriately by their family and society (Lestari and Wardhani, 2014). People with mental illnesses also often fall victim to inhumane treatment. For example, it is still easy to find those who have been restrained and isolated by their families and the communities around Indonesia. Families often hide or ostracize patients because they feel embarrassed or ashamed to bring people with a mental disorder to a mental healthcare facility (Daulima, 2014; Hawari, 2001). Consequently, many who need treatment are not taken for help. Stigma among family members and friends also has a major impact on the ability to socialize with family, friends, or community members once patients do return home from the hospital (Juliansyah, 2009). For these reasons, many patients prefer to stay in the hospital forever (Hawari, 2001; Lestari and Wardhani, 2014).

The medical treatment of people with a mental illness has not been satisfactory because of stigma (Hawari, 2001). Even if they do receive treatment at an asylum, healthcare providers often do not treat them with dignity or respect, nor do they provide optimal protection (Amalia, 2010). Many people, including nurses, still believe that mental illness cannot be cured and mentally ill people may not be able to function normally in society. In addition, the Indonesian government, the general public, and the media also portray the mentally ill as violent, incompetent, and as objects of ridicule (Hawari, 2001; Juliansyah, 2009).

CHAPTER 3

METHODOLOGICAL CONSIDERATIONS

3.1. Research Design: Grounded Theory

This study aims to explore the meaning of mental illness and stigma among mentally ill adults in Indonesia. A qualitative design is best suited to this research, since it aids in developing a deeper understanding of individual meanings and experience. Qualitative research is a process of inquiry of understanding based on several distinct methodological traditions of inquiry that explore a social phenomena or human problem. Denzin and Lincoln (2005) indicate that qualitative researchers “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (p. 3). Gaining insight into participants’ experiences and the meanings they apply to them requires the researcher to get close enough to participants in order to engage with them and their reality. The goal in qualitative research is to better understand not only how people construct meaning from their experiences but also to describe and interpret those meanings. In the end, the researcher builds a complex, holistic picture, analyzes words, and reports detailed views of informants (Creswell, 1998). The use of a qualitative method in this study allowed me to explore the meanings constructed by both patients and nurses related to stigma and mental illness in Indonesia from their perspective. It allowed me to go deeper into the data in order to reveal participants’ thoughts and experiences that were close to their realities at that particular place and time.

Grounded theory provides practical techniques and procedures for studying social processes, interactions, and relationships between and among people. It was selected as an appropriate research methodology to develop theory concerning the study of people living

with mental illness. According to Glaser and Strauss (1967), the aim of grounded theory is to generate theory and grounded theory can be defined as "the discovery of theory from data systematically obtained from social research" (p.2). According to Creswell (2007), grounded theory is a systematic research model that aims to develop a general explanation of a practice, action, or interactions.

Grounded theory methodology has evolved since the 1960s in the United States. The roots of grounded theory are in Chicago sociology, symbolic interactionism, and pragmatist philosophy (Charmaz, 2006). The first version of grounded theory was called "classical grounded theory," (the Glaserian approach) which was developed and articulated by Glaser and Strauss in their book, *The Discovery of Grounded Theory* (1967). Glaser contributed a positivist, logical, and systematic epistemology and methodology. Strauss contributed a pragmatic Chicago school epistemology and ethnographic methods. Grounded theory is an inductive method of research that uses constant comparative analysis to build and produce a theory grounded in the data rather than to test existing theory. Glaser and Strauss (1967) contended that much of research at that time consisted primarily of the verification of theory or the development of theory through logical deduction from "grand theories" and past studies rather than from the experimental data itself. At that time, they developed grounded theory as a reaction to the positivist paradigm held by social research.

The second grounded theory approach was developed by Corbin and Strauss (1990); Strauss and Corbin (1998). This grounded theory is also called a Straussian approach that differs from Glaser and Strauss's classical or Glaserian grounded theory. Strauss and Corbin provide a more prescriptive approach to grounded theory than the original method. Strauss and Corbin (1998) believe that the emphasis should not lie with collection of data, but rather

with how to analyze whatever data have been obtained. They stress that researchers need to be flexible, and should tailor their approach to their own needs. Strauss and Corbin modified grounded theory procedures and added additional tools for building a theory. Their methods have been criticized as forcing description of data rather than allowing a theory to emerge. Some have asserted that they employ too many tools, which may serve as a distraction from the research process (Melia, 1996). Glaser (2002) mentioned that Strauss and Corbin do not follow the methods as was intended with his approach to grounded theory.

The methodological approaches to grounded theory have evolved with changing socio-political and intellectual contexts (Dey, 2003) and these different approaches have resulted in differing interpretations of grounded theory. Glaser and Strauss themselves diverged in the 1980s, after which Glaser produced his own understanding of grounded theory methodology (Glaser, 1992). Glaser argued that "data emerges" and thus offers the same picture of facts to every researcher in the form of some objective truth. Strauss stressed that a researcher has to actively obtain theory from data. Researchers will thus place the focus on different aspects of the collected data depending on their background, beliefs, and values.

Charmaz (2000) argues that Glaser's (1978, 1992) approach is positivist since it wants to exclude the researcher's perspective and she recommends a set of procedures to render the data into identifiable knowledge. She also contends that Strauss and Corbin were also inherently positivist: "Both ... assume an external reality that researchers can discover and record: Glaser through discovering data, coding it and using comparative methods step by step; Strauss and Corbin through their analytic questions, hypotheses and methodological applications" (Charmaz, 2000, p.513). However, Charmaz (2000) goes on to argue that

Strauss and Corbin (1998) take a more "post-positivist" philosophical stance in the second edition of their book.

Grounded theory methodology has been utilised by nursing researchers since its development in the 1960s (Mills, Bonner and Francis, 2006). A review of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) found that grounded theory was the second most popular qualitative research method in published nursing papers (Schreiber and Stern, 2001). Grounded theory has proved useful for developing nursing knowledge and directing nursing practice as well as providing explanatory theories of human behaviour (Chenitz and Swanson, 1986; Morse, 2001; Wuest, 2007). Grounded theory provides great potential for nursing research because it seeks to discover issues of importance in participants' lives (Mills, Chapman, Bonner and Francis, 2007).

In Indonesia, grounded theory methodology has also been applied in the nursing profession, with the first grounded theory nursing project presented in 2000. However, grounded theory nursing projects in Indonesia are conducted mostly by Master's and doctoral students. These studies have focused on many nursing areas such as the concepts of caring, therapeutic communication, community nursing care, self-care, health-seeking behaviours, and chronic illnesses such as mental illness, stroke, and diabetes. The next section will discuss the third generation of a grounded theory approach: Charmaz's constructive grounded theory, which was adopted for this study.

3.2. Charmaz's Constructive Grounded Theory

I have chosen one of several methodological paths to conduct this study. I wanted a research method where I could use inductively derived data and construct theory from the study participants' experiences of stigma and mental illness. After reviewing qualitative

research methods and after an intensive discussion with my supervisors, I decided to use constructivist grounded theory, as it was the closest match to what I wanted to do. This research may be one of the few studies to theorize the experiences of stigma and mental illness among Indonesian adults using a constructivist grounded theory.

My worldview on knowing and knowledge affected how I conducted this study and consequently its outcome. The constructivist grounded theory research approach was introduced first by Kathy Charmaz in her book, *“Constructing Grounded Theory – A practical guide through qualitative analysis”* (Charmaz, 2006). Constructivist grounded theory can be considered the third generation of a grounded theory method. The methodological approach of constructivist grounded theory is rooted in Glaser and Strauss’s (1967) grounded theory but it is situated between positivism and post- modernism (Charmaz 1995). Unlike Glaser and Strauss, constructivist grounded theorists view their theories as situated in the context in which they were generated and are not fully inclusive of all contexts. It is a very practical approach that stresses the reflexivity of the researcher and captures the creative and dynamic character of the research process, recognizing that the categories, concepts, and theoretical level of an analysis emerges from the researcher’s interactions in the field and questions about the data.

Charmaz’s (2006) grounded theory design is consistent with a constructivist epistemology and ontology by “placing priority on the phenomena of study and seeing both data and analysis as created from shared experiences and relationships with participants and other sources” (Charmaz, 2006, p.330). She claims that a more objectivist approach, where the investigator’s role is to discover the truth that lies within the object of investigation, diminishes “the power of a constructivist approach by treating experience as separate,

fragmented and atomistic” (Charmaz, 2006, p.331). Data that are assumed to be objective facts and already exist in the world are, with an objectivist approach, to be discovered by the researcher to determine the theories they imply (Charmaz, 2006).

Glaser (2000) critiques Charmaz’s approach by stating that the co-construction of understandings between researcher and participant results in the “unwanted intrusion of the interviewer.” However, constructivists reject the idea of a neutral observer such as espoused by Glaser. Charmaz (2006) argues that first, theorising is an activity and grounded theory methods provide constructive ways to proceed with this activity. Second, the research problem and the researcher’s unfolding interests can shape the content of this activity, not the method. Last, the products of theorising reflect how researchers act on these. I adopted constructivist grounded theory in this study because its philosophical approach fits my constructivist philosophical assumptions and I liked the flexible approach to the method.

3.3. Research Setting and Participants

3.3.1. Research Setting

This research was conducted at the major psychiatric institution of West Java province in Indonesia (see Appendix A). This government-run hospital, which provides psychiatric and drug addiction rehabilitation services, as well as educational and research services, is one of the largest mental health hospitals in the Republic of Indonesia. At the time of my data collection in 2013, the total hospital staff of 1037 comprised 473 nurses, 56 physicians, 9 dentists, 12 pharmacists, 12 psychologists, and 119 non-nurse paramedics. In addition, there were 356 administration and management personnel to support administrative processes. After obtaining ethics approval from the University of Ottawa (see Appendix B), I met the director and the head of Research and Education of the hospital to explain the study

and its purpose. My research supervisor also met with the management and nursing staff. I provided written material describing the study and to explain the need for studying adults with mental illness experiencing stigma. In addition, my research proposal was presented to hospital management and the nursing staff.

3.3.2. Participants

According to Creswell (1998), researchers using a grounded theory approach choose participants based on their ability to contribute to an evolving theory and to give in-depth accounts regarding the phenomena under study. According to these principles, participants were drawn from both male and female patients, as well as from registered nurses (RNs) practicing at the hospital. All participants were recruited by the researcher and only adults who self-identified themselves as Indonesian citizens, had the ability to read and write, were at least 18 years of age or older, and, in the case of the patients, admitted that they had experienced mental illness and stigma, were included in the study. All participants provided consent to participate (see Appendix C). A total of 30 participants (15 patients and 15 nurses) were recruited, which, according to Charmaz (2006), is more than enough to ensure data saturation.

The initial contact with nurse participants was made through a presentation of the study project. This initial meeting was followed by a mutually agreed upon time to meet. All interviews were conducted at the hospital. Environments for the interviews were selected to provide privacy and quiet to make the participants feel comfortable. Contacts with patient participants were assured by the researcher after discussion with the healthcare team and management staff, although they were not recruited by members of the healthcare team. Floridly psychotic patients and/ or those with severe symptoms of their mental illness were

not recruited. All interviews were conducted on site at the hospital, with patients being interviewed in the morning and afternoon, and nurses before, during, or after their work shift. During the 40-60 minute interviews, participants were asked a series of questions. No participant received any direct benefit from his or her participation in this research project.

3.4. Data Collection Methods

Data collection methods play an important role in providing information useful to understanding the processes of study participants' perceptions of their experiences. In this study, the data collection method involved direct interactions (interviews) with 30 participants on a one-to-one basis. Other different sources of information were used including mute evidence, field notes, and memos. The resulting triangulation of this data helped me to develop theories that explained the underlying relationships among the categories that emerged from the multiple forms of my data. Each data source contributed to my understanding of participants' perspectives on stigma and mental illness.

3.4.1. Semi-Structured Interviews

Interviews were the primary method of data collection used in this study. Interviews are a common method for collecting data in qualitative research studies and are used to elicit information about what people do, think or believe about a particular topic (Minichiello, Aroni, Timewell and Alexander, 1995). Charmaz (2006) argues that "an interview is contextual and negotiated and that the result is a construction or reconstruction because interview stories do not produce prior realities but instead provide particular accounts from particular points of view that serve particular purposes" (p. 47). The recommendation for data collection in grounded theory research is that 20 to 30 individual audio-taped interviews are procured or sufficient interviews conducted for saturation to be reached when no new

data emerge (Creswell, 1998). In this study, thirty semi-structured interviews were conducted in the Indonesian language (Bahasa Indonesia) and translated by a certified translator (see Appendix D). All translations were verified by the researcher.

Semi-structured interviews served as a source of data collection from the participants to understand their opinions and perceptions regarding stigma and mental illness. At the beginning of the interview sessions with each participant, I introduced myself again, explained the purpose of the study, and the confidential nature of the data collected. This gave participants an opportunity to ask any questions and helped establish a comfort level before the interview began. I was concerned about appropriate location and timing of interviews for participants, tried not to take up too much of their time, and was prepared to give emotional support to participants when necessary (Holloway and Wheeler, 1996). I asked if the participants had read the participant information sheet and ensured that they were fully informed about the research. I completed informed consents prior to the start of the interview (translated to Bahasa Indonesia). Before the interviews began it was established that they would take 40-60 minutes unless the participant wished the interview to be shorter or longer.

All 30 participants who agreed to be interviewed attended on the scheduled day of the interview and the interviews were conducted in hospital meeting rooms and nurses' offices. The decision to use face-to-face interviews worked very well in this study. To ensure a complete and accurate interview record, all interviews were digitally audio-taped with each participant's permission (Minichiello, Aroni, Timewell and Alexander, 1995, p. 98), and I took hand-written field notes and memos. I found that this method allowed me to adopt a more personal, conversational tone during my interview. Also, participants seemed to feel

more at ease, and I felt more comfortable. During the interviews, I used interview guide(s) (see Appendix E), which contained a set of brief, general questions, a typical outline, or a major theme (Chenitz and Swanson, 1986). I asked my questions in the order they were presented in the interview protocol. During this process, I gave participants enough time to reflect on and consider their responses since I did not want them to feel pressured to respond before they were ready. Immediately following the interview, I summarized the information gained, and rechecked my field notes and memos. I gave the participants a chance to ask more questions. Then, I expressed my gratitude for their time and willingness to participate in this study.

3.4.2. Mute Evidence

Mute evidence or document review is a way of collecting data by reviewing existing documents. Documents or mute texts comprise a variety of written, visual, and physical material that ‘document’ human activity over time (Merriam, 1998). Along with interviews, memos and field notes, mute evidence was part of my data collection strategy and formed the triangulation of data that served to improve the probability that interpretations of the data will be found credible (Lincoln and Guba, 1985). Document analysis provided information leading to a better understanding of the questions of stigma and mental illness and provided a diverse amount of information from a variety of sources.

Mute evidence collected in this study was both hard copy and electronic, including nursing reports and logs, nurse performance ratings, meeting minutes (pre- and post-conferences), newsletters, and other materials such as the hospital’s motto, vision, and mission statements. Also included were components of a mental health nursing management program that had been implemented in the hospital, records of visits by members of the

community mental health nursing (CMHN) program, nursing care plans (NCP), patients' instructional materials (group therapy and rehabilitation therapy), and documents that provided information on how mental health nurses provide nursing care to their patients. In addition, I collected data on the philosophy of nursing and the standards of nursing care, as well as on the operation of the institution. Some advantages of these kinds of documents are that they are relatively inexpensive and a good source of information. All of this mute evidence was important in guiding my interpretation of the participants' beliefs and attitudes, especially as it related to nursing practices and mental health nursing management programs.

3.4.3. Memos and Field Notes

In this study, field notes and memos were written during the interviews. In general, field notes and memos provide descriptions of hospital wards settings, nurses, and patient activities.

Memos

During data collection, memo writing includes the interviewers' thoughts and interpretations about the interview, ideas about the emerging theory, and the research process including questions, gaps, as well as the analytic progress of the research. Memos are essentially a way to document thoughts and create a tangible paper trail that explains the researcher's thinking process throughout the research project. Written accounts provide insight into the meanings, perspectives, practices, and events not obtained in interviews. After I conducted an interview, I read my hand-written memos. Then, I continued to make field notes of my general impressions and observations.

Field notes

Field notes are used to record observations and reflections on the data, as part of the reflexive approach to the ongoing analytical process (Charmaz, 2006). My field notes were written into a notebook after each interview to construct a context for making sense of the data later in analysis (Patton, 2002). They allowed me to collect information on important nonverbal communication, and to make general observations of participants' sights, sounds, interpretations, and gestures. Also, smiles, laughter and other types of humour were noted. In general, field notes were about certain interactions where I was not part of the interaction. I added to the field notes and memos immediately upon leaving the hospital, contextualised them in full thereafter, and downloaded them to a computer file.

3.5. Data Analysis Method

After all interviews were completed, they were transcribed verbatim and checked for accuracy. Since the interviews had been conducted over two months, I analyzed each interview transcript sequentially. Data analysis in this study occurred over a period of 12 months in total. At first, I thought I would use data analysis following the basic principles of constructive grounded theory (Charmaz, 2006). Heath and Cowley (2004) propose three main stages in grounded theory data analysis: "Initial coding, intermediate phase, and final development." Based on these stages, Charmaz's (2006) constructive grounded theory starts with initial coding, focused coding (intermediate phase), and theoretical coding (final development). However, I decided to employ Paillé's (1994) method of data analysis to organize and manage data. It mirrors Charmaz's (2006) method of data analysis by adapting the basic principles of constructivist grounded theory and displaying the data analysis in a sequential form: *codification, categorization, linking categories, integration,*

conceptualization, and theorization. Paillé's (1994) data analysis can also be divided into three stages: codification and categorization (initial coding), linking categories and integration (intermediate phase), conceptualization and theorization (final development). Although Paillé's data analysis steps are presented as separate entities, the researcher must not view them as mutually exclusive, nor assume that the progression between each step is linear. It is a system process of analysis. During my analysis process, I found that Paillé's method of data analysis was very useful, helping me to organize my data in a sequential manner.

Table 3.1: Grounded Theory Data Analysis (Paillé, 1994)

1. CODIFICATION
2. CATEGORIZATION
3. LINKING CATEGORIES
4. INTEGRATION
5. CONCEPTUALIZATION
6. THEORIZATION

3.5.1. Codification

According to Paillé (1994), codification is the first step in data analysis. Charmaz (2006) indicates this step as the first phase of the "initial coding" data analysis. The objective of codification is to name, reveal, summarize, and label the contents of the transcriptions obtained from the interviews. Codification involves examining the data line-by-line (coded line-by-line), searching for concepts, sub-categories, and patterns. This step incorporated the

coding of each sentence and each incident into codes. My interview transcripts were coded word-by-word, line-by-line, and segment-by-segment.

I first coded the data from Mrs. AB's (N1) transcript using a line-by-line action word concept. Charmaz (2006) highlights that grounded theory uses special terms for participant known as "in vivo codes." They serve as a symbolic marker of the participant's speech and meaning, serving to crystallise and condense meanings. In vivo coding provides an important check on the significance of the codes to the participants' specific meanings and experiences. During this step, I found hundreds of codes. I put codes in the right margin of each transcript. Paillé (1994) has suggested that the researcher should limit the number and construction of codes, and remain grounded in the data. In this step, I arranged important words, perceptions, and experiences into organized codes (the process of forming all codes). This exercise, which is suggested by Paillé (1994), helped identify overlap between initial codes and the formation of categories. After all codes are formed, the next step is categorization.

3.5.2. Categorization

Categorization is the second step of Paillé's data analysis. It is the process of developing main categories and sub-categories (Pidgeon, 1996) to determine the categories from the results of the codification process. Charmaz (2006) indicates that this step is the second phase of her initial coding. All codes were viewed in detail and put in the appropriate category, and there were similarities. During categorization, the most significant or frequent codes were sorted, synthesized, integrated, and organized. I grouped together all codes that appeared related or that seemed to be the most important for stigma and mental illness. I moved back and forth from codification to categorization. Data were compared to data, and

incident to incident, to develop categories. I analyzed codes, regrouped and classified them to create hierarchies. During this process, I employed constant comparison data analysis as suggested by Charmaz (2006) to move across the data, constantly comparing and contrasting in the search for similarities and differences. Because a grounded theory relies on the constant comparison of data, the researcher's sensitivity to the phenomenon being studied becomes more refined, helping to make sense of the data, name phenomena, extrapolate meanings, and link different parts of the study as they evolve (Paillé, 1994). This method helped to identify overlap between my initial codes and the formation of categories. My analytical process, which included the codification of interviews and categorization of emergent concepts, produced five mutually exclusive categories: (1) treatments; (2) violence; (3) fear; (4) constructing cursed citizens; and (5) stigmatization. According to Paillé (1994), each category is mutually exclusive, meaning that each category defines, in rich detail, a specific aspect of analysis.

Table 3.2: Final Categories

1. TREATMENTS
2. VIOLENCE
3. FEAR
4. CONSTRUCTING CURSED CITIZENS
5. STIGMATIZATION

3.5.3. Linking Categories

Linking all categories is the third step of grounded theory analysis (Paillé, 1994). This step is the first phase of "focused coding" of Charmaz's (2006) analysis. Although the

process of linking categories is largely an empirical endeavour, it is nonetheless influenced by theoretical perspectives incorporated into the research by the researcher (Paillé, 1994). In this step, I seek to connect and link the categories of treatments, violence, fear, and constructing cursed citizens together to see the similarities and differences among them, which would be finalized in the conceptualization step (fifth step of analysis). All categories were related to each other. This step also involved specifying the relationships between the categories and concepts. Charmaz (2006) calls it diagramming, where a series of visual diagrams help to explore relationships between categories to discover potential links. During this process, I moved through the categories, subsuming some as sub-categories, leaving others as distinct but linked, and brought them together.

3.5.4. Integration

Integration is the third step of grounded theory analysis (Paillé, 1994). In this step, after all categories and the core category have been determined, the researcher integrates all categories. Charmaz (2006) indicates this step as the second phase of her focused coding. Strauss and Corbin (1998) call this step “selective coding, which is the process of integrating and refining categories” (p. 142). The primary goals of this step in the analysis were to develop an overarching theoretical schema explaining how each of the categories related to each other, and to identify a core category that explained the experiences of participants.

During this step of analysis, I looked back to re-read my memos and my field notes to analyze schemas in order to find other common threads that had not yet been found. As a novice researcher, I found this integration step one of the most difficult parts of the analysis. I was faced with the challenge of pulling all the threads in the analytical research together

and connecting all the themes in my memos and field notes to build the framework of a “reasonable” explanation associated with stigma and mental illness.

3.5.5. Conceptualization

Conceptualization is the fifth stage of Paillé’s (1994) grounded theory data analysis. This step consists of attempting to find the structural organization and relations between categories. Charmaz (2006) calls this the first "theoretical coding phase." Conceptualization is the process of the development and clarification of the emerged concepts and ideas and of clarifying concepts with words for conceptual definitions. In this step connection and linking among all categories was finalized, enabling the understanding of the research phenomenon in all of its complexity. Explanatory links were established between the nature of the phenomenon, its causes and consequences for mental illness and the stigmatization process. This step refined concepts and categories for theory development and helped me to identify "constructing cursed citizens" as a basic social process.

3.5.6. Theorization

The sixth and the last step of Paillé’s grounded theory data analysis is theorization. Theorization is the process of construction or substantiating the theory (Charmaz 2006; Paillé 1994). A substantive theory in grounded theory refers to a set of explanations that accounts for phenomena within a specific or substantive area. Theorizing is not something that is done at the end of the study, but rather represents the product of a rigorous analytical process (Paillé, 1994). A researcher using grounded theory does not have to create/produce a theory. For Charmaz (2006) writing a theory is based on the interrelationship of the categories from the previous steps of analysis. This study has resulted in my own representation on stigma and mental illnesses that emerged from examining participants’

perspectives on their own experiences. This substantive understanding was produced after the researcher followed each of the data analysis steps. It is context-specific and is concerned with the process from the perspective of these adults participating in this study. Finally, I created a schema that reflects the empirical data used to answer the research questions. In this study, a complete account of the theoretical production (representation) is provided in the results section (Chapter 4).

3.6. Rigour

Hutchinson and Wilson (2001) state that researchers using a grounded theory method must address the issues of believability and rigour in their research. Rigour is a means by which researchers demonstrate the legitimacy of the research process. To ensure that this study was rigorous I needed to tackle the issue of my role in the research as a research instrument. The identification of criteria used to evaluate research that was carried out using a grounded theory approach helps one to determine the trustworthiness of the study by evaluating its strengths and limitations.

Different criteria of rigour exist in scientific inquiry. For example, Lomberg and Kirkevold (2003) use the concepts of *fit*, *work*, *relevance* and *modifiability* to judge the quality of a theory. Denzin and Lincoln (2000) identify four different criteria, including *credibility*, *transferability*, *dependability* and *confirmability*. In this study, I chose to adapt and employ Chiovitti and Piran's (2003) rigour requirements for qualitative data, which include *credibility*, *auditability*, and *fittingness*.

Credibility refers to the use of accurate descriptions or interpretations of a human phenomenon so that the individuals having the experience would recognize their experience from the descriptions, or others would be able to recognize the experience after having read

about it (Sandelowski, 1986). Credibility is used “to assess the truth-value of findings by addressing the inductive nature of grounded theory and allowing participants to speak through the data and to ensure that the phenomenon investigated was accurately identified and delineated” (Chiovitti and Piran, 2003, p. 430). Credibility was enhanced in this study by gathering data from multiple sources: interviews (which were transcribed verbatim), field notes, and memos. Field notes and memos were not transcribed but used to contextualize the data gathered during the interviews. Staying close to the data by word-by-word, line-by-line, and using in vivo coding, facilitated the construction of a grounded theory that reflects the participants’ experience of stigma and mental illness. Keeping raw data, field notes, and memos have provided an audit trail of the various steps, from data to analysis and interpretation. In addition, during data analysis, I met personally and contacted via email my dissertation supervisor regularly every two weeks to review all of the material collected. I also discussed with him the analysis process and other issues that arose related to my data collection and data analysis process. Furthermore, my interview transcripts, which had been translated to English, were read and reviewed by my supervisor.

Auditability is the ability of other researchers to follow the methods and conclusions of the researcher (Chiovitti and Piran, 2003). Auditability relates to consistency of findings, meaning that another researcher can clearly follow the thought processes used by the researcher in the study and can arrive at a comparable conclusion (Sandelowski, 1986). Auditability is enhanced by indicating the criteria used to formulate the researcher’s thinking, and by detailing how and why the participants in the study were chosen (Chiovitti and Piran, 2003). I carefully documented the research process and findings. I kept a journal,

tracking all the subjective decisions that I made and their rationale. All decisions were documented throughout the research process.

Fittingness is also referred to as transferability; it “pertains to the probability that the research findings have meaning to other similar situations” (Chiovitti and Piran, 2003, p. 433). Another definition is that study findings are meaningful and applicable to readers in terms of their own experiences, and the findings are reflective of the life experiences being studied (Sandelowski, 1986). According to Chiovitti and Piran (2003), fittingness can be accomplished by delineating the scope of the research in terms of participants, setting, and level of theory generated, and by describing how the literature relates to each category that emerged in the theory. During the coding process, all coded data were reviewed by my dissertation supervisor, providing an external check to the findings. This independent analysis of data by another researcher or expert serves to validate findings (Sandelowski, 1986).

3.7. Translation Process

According to Temple (1997), research involving the use of more than one language needs to include a thorough description of the translation-related issues. Translation was an issue because data collection (the interviews) was conducted in Indonesia using the Bahasa Indonesian language, yet the results needed to be written in English. Fenna, Tineke, Hans and Dorly (2010) indicate that issues related to the translation process need to be addressed prior to data collection and analysis because there is potential for the meaning and intent of the research to be lost if the process of translation is not appropriate. Language differences were considered an issue that might hinder the transfer of participants’ meanings or might result in loss of their meanings. The quality of data translation can influence the equivalence

and accuracy of findings (Frederickson, Acuna and Whetsell, 2005; Schultz, 2004; Temple, 2002).

These issues could have had an impact on the validity of this research if translation was not comprehensive and accurate. Two issues must be addressed related to translation in this study: who undertook this translation and the translation procedure used. The translation process for all interviews was conducted between October and November 2013 in Jakarta, Indonesia. Translation was done by myself with one professional translator from the Binawan English Language Center (BLC) (see Appendix D), Jakarta. I chose this translator based on his competencies and ability. Before translation, he had signed a confidentiality agreement affirming that he would not share any information related to the interview transcripts. Since this translator was not involved in the research process, however, a debriefing was needed with him for clarification and evaluation of all interviews. This translator was responsible for converting all information on the interview transcripts from the Indonesian language to English. To convert this information, he used his knowledge of both languages. However, since he had no educational background in the medical field, he needed me to review and recheck his English translation results because some medical terms and words in the Indonesian language needed to be put in the correct manner in English. I needed to verify the accuracy of his work. During this process, I worked carefully to verify that the English translation was correct for words, terms, and sentences. I went back to look at each interview translation and I could see that this process was time consuming. For me personally, being able to review and verify the English transcripts was not difficult. Although my native tongue is Buginese from the Sulawesi Island, I have spoken both Bahasa Indonesian and English since childhood and still use them even now. My familiarity with the

Indonesian language enabled me to understand nonverbal cues during the interview, which added to my understanding of the experiences of the study participants. This also helped in the review of all English translations. I have also reached a level of ease in shifting from English to the Indonesian language and *vice-versa*. Such skills helped me to write my thoughts either in English or the Indonesian language in my field notes and memos.

During this translation process, the translator and I remained faithful to the story of the participants. We carefully selected words that were the same or least closest to each word for each statement from the participants. The idea was to convey the message in English in the most accurate manner. Also, as a part of the translation process, all English translations were reviewed and checked by two nurse colleagues who have International English Language Testing System (IELTS) scores of 7.0 and higher. They worked to review and compare the original interviews with the translations done by the expert translator. During this process, we made sure that the English translations were comprehensible yet faithful to the interviews conducted with the participants. After all transcripts were translated into English, they were brought to Ottawa, Canada, for data analysis.

3.8. Ethical Issues

Ethical issues are a central issue in this research. Socially sensitive research studies deal with issues in which a potential social risk exists for participants because the group being studied is particularly vulnerable, disadvantaged, or powerless (Gibson, 1996, Owen, 2001, Ziebland and Wright, 1997). People who have a mental illness may fall into all of these categories. Some authors have questioned the ethics and suitability of researching vulnerable groups, including those with severe mental illness (Moyle, 2002; Usher and Holmes, 1997). It is important that some critical areas were addressed in this research: (1)

informed consent and right to withdraw (2) confidentiality and data protection, and (3), potential harms.

Informed consent included providing participants with information about their rights and responsibilities within the research project and documenting the nature of the agreement. The researcher consciously and deliberately attempted to clearly and fully provide the potential participant with information about the research project. The consent form clearly explained the study objectives and stated that participants have the right to accept or refuse to participate. Participants were informed that, at any time, they could withdraw from the study without any prejudice. Prior to each interview, participants were required to read and sign two copies of the consent form and they were given one of the copies.

The researcher was responsible for protecting all data gathered within the scope of this project. For that reason, confidentiality is also a principle ethical issue in this study. Confidentiality is commonly viewed as similar to the principle of privacy (Gregory, 2003). Therefore, the information a patient reveals to a researcher is private and there are limits on how and when it can be disclosed to a third party. Participants involved in the study must be assured that their data will be kept anonymous unless they give their full consent otherwise. In other words, what has been discussed or disclosed by participants will not be repeated or shared without their permission. Anonymity refers to the act of keeping individuals nameless in relation to their participation in a research project, and no names were used in this study. Each participant was attributed a random, alpha-numeric code in order to make it impossible for anyone to link a transcription to a particular participant (P1 for patient 1 and N1 for nurse 1). All digitally recorded interviews were downloaded into a private password-protected computer in Jakarta, Indonesia. They were then brought back in

person by the researcher to Ottawa for transcription. The content of the interviews (tapes and transcriptions) was never handled by a third party other than the main researcher's supervisor. All confidential data and materials were kept locked in the main researcher's supervisor's office at the University of Ottawa, in the space held by the University Research Chair in Forensic Nursing. Data will be kept for a period of five years following the completion of the study, after which the material will be destroyed (transcriptions will be shredded and tapes demagnetized).

Potential harm is another important issue in this research. It is important that researchers recognize when they are carrying out research that is socially sensitive and understand their responsibilities to participants (Lee and Renzetti, 1993). One responsibility of the researcher is to protect all participants from harm while they are participating in an investigation or as a result of the study. Also, there is an inherent risk to the researcher in carrying out the study, especially relevant to research with participants who have a mental illness. Before this study began, the researcher informed each participant about the research and asked his or her consent to participate. Participants were given information relating to the research purpose, procedures, and the potential psychological discomfort to the study participants was explained. Participants were exposed to risks greater than those encountered in their normal daily life, but the researcher was careful not to embarrass, offend, or frighten any of them. In addition, participants were informed about the length of time it would take to participate and the nurses to contact in the event of an emergency.

CHAPTER 4

RESEARCH RESULTS

The purpose of this chapter is to provide the study results from the data analysis of interviews of 30 participants (15 nurses and 15 patients) in the Marzoeki Mahdi Mental (RSM) hospital. The use of Charmaz's constructive grounded theory method has led to five discrete but interrelated categories: 1) Treatment of mental illness; 2) Violence; 3) Fear; 4) Constructing cursed citizens; and 5) Stigmatization. These categories are mutually exclusive although all of them are linked to one another.

4.1. CATEGORY 1: TREATMENTS

4.1.1. Traditional Treatments

Possession by devils, demons, spirits

Some local cultures and religions still contain some concept of demonic possession in which it is believed that all diseases of the body and mind are caused by "sickness demons or devils." According to one participant, people are still influenced by the past; if a person suffers from mental illness, it is because he is possessed by his grandfather's devils or spirits.

Illness caused by sin

Some people still assume that mental illness is caused by a sin either conducted by the patients or their families. Therefore, it is a disgrace for the family if a patient suffers from mental illness.

Our societies vary. Also, their levels of education vary. For the majority, they still assume that mental illnesses are caused by a curse. What is it called? A curse ... sin, behaviour or action in the past ... The patients' past. Could be also their family's past, either their mothers or their fathers [or their] grandmothers or grandfathers' past ... It is also heredity ... Sure ... Patients with mental illness are considered destroyers etc. They are considered dirty

people. Because of a curse and [because they are considered] sinful people. (N6: p.13-14).

Humane Traditional Treatments

According to the research participants, most of the patients who suffer from mental illness have been brought first to people who practice what we consider alternative medicine. These alternative treatments are often the first choice of the patients, family, and the community. Many family members deny that their relatives suffer from mental illness, or if they do not deny it, they believe that mental illness is caused by demonic possession.

Most [patients] went everywhere for alternative healers because they assume that they are possessed by demons; they are stressed because of this, because of that. So family members think that [there is] no need to go to a mental hospital. They go to chaplains first, to this place first, everywhere first ... Yes, most, if possible do not go to a mental hospital for treatment. The majority go to the hospital as the last option. Some families say, "I have lost everything" (N11: P.13).

As mentioned earlier, there are several kinds of alternative treatments available in Indonesian society from "smart" people, who include Islamic scholars or teachers (*Kiyai* or *ulama*), paranormals, chaplains, and shamans (*dukun*). One patient participant insisted he did not believe in shamans but he had no choice but to agree to his parents' wishes that he be treated with one. However, after having treatment with a *dukun*, he stated that he had no positive result.

[...] They brought me to the shamans. All 'crazy' people have to, go to the shamans. Yes, I go to the shamans ... my father too, in order to cure my illness. My father was confused. We went to Bengkulu and stayed at my family's home. At the shaman's, there was a chicken to be sacrificed. Voodoo is like that too. Whatever the shaman asked, we obeyed. But after that, nothing happens. This shaman is from there ... His clothes are all black and he never takes a bath. It is really true. ... There are many kinds of these shamans. Some bring *tuyul* [a small belief]... Shamans are poor. They make people rich but their homes are huts. At this shaman, I was chanted over with water. Someone wanted to bewitch me. There was lemonade opened ... It was seen in the lemonade that a friend of mine at my school [wants to put a spell

on] me. I don't know how he knows that I have a friend at school who was bad to me. Actually, I didn't believe it but because of my condition [from which] I really want to recover, therefore, I just followed. After going back home from Bengkulu, there was no result. As usual, I am depressed again (P10: p. 23-24).

In Indonesia, going to a person with paranormal traits is also a popular choice of alternative treatment for patients and their families. Apparently specializing in treatments directed at the specific problems of patients, paranormals provide invocation treatments. However, some patients feel that visiting a paranormal can only make later treatment with a medical professional more difficult.

[Paranormals] are discredited. Furthermore, they are only ordinary people ... At the paranormal, [sick people] are given invocation treatments. They don't know, they are unconscious ... medicines and invocations. They become blank; many people do really forget ... After ... doctors [find it] difficult to treat them. I don't want to have treatment like that (P7: p.6).

Traditional Chinese medicine, which includes various forms of herbal medicine, acupuncture, massage, and dietary therapy, is another treatment choice for mental illness. As one patient participant describes:

I have been in traditional Chinese [treatment] too. A Chinese healer was there ... His name is KKL. I took his Chinese pills ... Yes I was there [at the Chinese alternative] ... Then, this Chinese person did wu wu wu wu wu [shows a method of healing proces by blowing air from his mouth] to cast out demons, my negative energy, so that I can spend my money for his treatment. That devil [laughs]... that devil ... [unclear]. Devil ... puooooooooohhh goes away. Yes, it is true ... like that. When I cry out loudly... [unclear] the devil goes away, like that (P3: p.9).

Inhumane Traditional Treatments

Many Indonesians who seek help from traditional healers experience violence at the hands of these healers. Some of these treatments are thought to release the demons embedded in their bodies. Many are forced to stop taking any medications they were on and required to ingest those given to them by these healers.

Oh yes ... if patients have treatment at the smart people, what I know and I see with patients, is usually they aren't allowed to take medicine ... Yes, they aren't allowed to take medical medicines. In addition, they have more prayer treatment ... such as drinking pure water, *zikir* or *wirid* [prayer]; they focus more on these. (N6: p.12-13).

Others endure treatments such as near drowning, whipping, or forced bathing. One patient describes his treatment regimen.

Yes, I was there for one and half months. I was bathed at midnight. [The shaman] wanted to use witchcraft ... [unclear], he fought me. I was bathed at 1 pm. I wasn't asleep. I was whipped... I was whipped similar to the goat. I was there for one and half months, however I was not healthy, I am not better (P2: p.6).

Another patient thought his treatment was more suited for people with substance abuse issues.

In Cisaung Parung ... Whipped. I was flushed, soaked. Only substance abusers are always treated like that. For 30 minutes, I was bathed, plunged ... This water? The water marks, I do not know. [Laughs] Probably urine or what it is? I was similar to a water buffalo, bathed as if I was not a human being anymore. I was whipped to have a bath ... It was like being an animal, a water buffalo. (P2: p.7).

Some patients were forced to eat strange foods, like one who was fed raw eggs and chilies, or another who had to eat leaves. Another type of inhumane but popular treatment undertaken by traditional healers is a hard massage or *penyek-penyak* that is performed on the entire body. The purpose of this hard massage is also to release or to remove the devil from the patient's body.

I was treated like this ... [shows], my head like this ... Whew... hot ... hot, very hot. Sometimes the shaman is violent ... pounds the table ... brukkkkk, like that ... "Then, the devil in my body was taken out," he said. They think that there is a devil ... Yes, they do. My brothers think that too. I got a lot of these kinds of massages when I was angry. My feet were massaged. (P3: p.8-9).

In the end though, because there is no improvement from these traditional treatments, patients are brought to the hospital with obvious physical problems.

4.1.2. Barriers to Modern Treatment

Economic

For many people, being poor presents a barrier to both access and treatment for their mental illness.

First ... [is the] economic factor ... in Indonesia, there are many poor people ... To get access to healthcare facilities is difficult. Even just for transportation fees, it is difficult [and] for treatment fees (N9: p.11).

They don't have money if they want to come [to the RSMM]. They don't have it (P7: p.8).

Many patients and their families believe that it is too expensive to have treatment in the hospital.

Actually, patients and family are integral...they assume that having treatment in healthcare facilities needs a lot of money (N6: p.11).

Financial issues make family members angry with their relatives who are mentally ill. Treatment for mental illness is expensive because it usually takes a long time for patients to recover. One patient mentions that his family members are angry because they have spent a lot of money on his recovery. For patients who do not have health insurance, like *Jamkesda* or *Jamkesmas*, the financial costs are high, and even with insurance, hospital visits are expensive.

No.... completely not at all. I do not have support that gives me spirit. [My spirit comes from within myself]. For example, just now my younger sister went home from here; she was angry because her money has finished. My mother and my brother are angry because their money has finished; [being] brought here, it needs a lot of money. I am the backbone of my family, I care for my family. For that reason, because of the money reason, [its] unbelievable, I don't have support at all (P1: p.5).

Distance

Distance is another barrier to treatment in a mental hospital especially for people who live in the villages or remote areas.

In the villages, more of them go to the alternatives because it is [too] far [to the health facilities] sir. Probably, they just go to the Puskesmas (public health center). For the majority, they go to the alternatives (N14: p.8).

Lack of Knowledge

Many people do not know where to go for help beyond alternative healers. Because many families and communities do not understand mental illness, they fail to seek the right information that would help sufferers. If people have a physical illness, they know where to go for treatment, but not for mental illness.

You are right, sir. If [they have] a physical problem, like hypertension, it is not a problem. People know that they will go to an internist. But, when certain conditions such as violent behaviour, being sleepless, talking to themselves - these conditions are ignored. They don't know where to go ... yes; they don't know where to go. They only know *gila* [crazy] in their language. They only know that (N1: p.14).

According to one nurse participant who works in family assessment, healthcare professionals do not do a good job in promoting understanding about mental health facilities and what they can offer.

[There is a] lack of knowledge that mental illness actually has medication [that can help]. There is minimal healthcare manpower to provide information and education about mental health to them, to the community. (N3: p.11).

4.1.3. Modern Treatments

Medical care at the hospital

At the Rumah Sakit Marzoeki Mahdi (RSMM), mentally ill patients are brought by their family, community members, or police officers. The majority of admissions to the RSMM come through either the IGD [emergency unit] or polyclinic. Only physicians and

nurses have the authority to admit patients to the hospital. As one nurse participant stated, those who come through emergency usually need acute care and are hospitalized; those coming from the polyclinic will be treated on an in-patient basis only if they are agitated – otherwise they will continue to be seen as an outpatient. (N1: p.4). Some same-sex wards are increasingly favored to protect women inpatients. When patients come to the hospital, they are assessed, monitored, and often given medication and care from psychiatric nurses, psychiatrists, clinical psychologists, psychotherapists, pharmacists, social workers, and physiotherapists. If a person receiving treatment in a psychiatric hospital is assessed as at particular risk of harming themselves or others, they may be put on constant or intermittent one-to-one supervision. Patients may be physically restrained or if their behaviour warrants it, they may be allowed leave for periods of time.

Patients who are hospitalized are provided with adequate food, which, as one nurse noted, provided psychological comfort to those who feared hospital treatment (N10: p.12). However, the food is served on *platos* or aluminum plates, which was a problem for another nurse, who believes that the patients deserved better.

They are hospitalized. I take care of third class patients. They eat on platos, right? It is sometimes disgusting right? Actually, it isn't the problem about believing or not believing, but eating on platos, foods are divided, rationed, [and] we don't know if the platos are clean or not clean. (N9: p.5).

The hospital also provides a kind of uniform pajamas for all hospitalized patients, although one nurse participant complains that these label the patients as “mentally ill.”

[...] How, it is a pity sir. You know, our patient clothes are from private donations. The hospital only provides the uniform that the patients use. They are from the hospital, the pajamas. Actually, they are not suitable [because] they label. Yes, it is a label, stigma. Casual clothes are from us. When this ward was opened for the first time, we asked for casual clothes, but they gave pajamas again (N2: p.11).

Psychiatric Medications

Psychiatrists provide medications for the patients, which are used to treat the symptoms of mental disorders. At the RSMM, medications are sometimes used with other treatments such as psychotherapy and group therapy activities. One patient participant was relatively satisfied with his treatment, understanding that he has to continue his medications because he is not healthy yet (P2: p.4). However, another complained he hasn't seen a doctor yet and feels he's just wasting time in the hospital.

It is a problem for me... I am only detained, and my doctor is not clear either. Because I am not a sufferer, what I want, I just want to manage my family first... it is only about my doctor, doctor F. Doctor F is on vacation, he has no substitute or other person in charge. Yesterday, I learned that he does have a substitute. I don't know him yet. Ouch!!! [Hopeless] (P6: p.4).

Electroconvulsive Therapy (ECT)

At the RSMM, the hospital staff provides Electroconvulsive Therapy (ECT), in which seizures are electrically induced in patients to provide relief from psychiatric illness. However, ECT is now usually used only as a last option of psychiatric intervention for patients with major depressive disorders, schizophrenia, or catatonia.

Standards ... about standards, I see that from time to time, these standards are different. For the therapies ... there have been many improvements. In the past, medicines were the first. But if it [those didn't work, [we] used ECT. It was always about this ECT... and ECT again ... But now, I see that [treatment] is with oral therapy first. If oral therapy doesn't work, then injection therapy is performed. If this therapy isn't successful, then ECT therapy is performed (N5: p.1).

4.1.4. Nursing Care

Nursing care in the hospital

At the RSMM, mental health nurses use Standard Operating Procedures (SOPs) for their nursing care. These SOPs provide guidance for their nursing care performance,

competencies, and required learning. Each SOP is related to a specific diagnosis, and it describes each critical and sequential step one has to perform in a task in order to assure its expected result. It aims to obtain more uniform service quality, which is related to the clients' rights to receiving nursing care according to their needs.

In nursing care delivery, we have standards; so there are some problems which usually happen in the ward, such as 7 diagnoses, sometimes 9 [diagnoses] with both therapeutic communication and individual coping. During my time here, there have been 6 ...7... 8 and can be more. For the SOP, actually we do tasks, for example, there is planning, patients' allocation. All are distributed, for example, I have 5 PAs [associate nurses]. So, all patients have a PA as their nurse and if the one assigned is off, the patient is referred to the nurse who replaces her. All nursing care strives to develop therapeutic communication, a trust relationship with the patients ... Furthermore, we work directly with the patients since they don't recognize their nursing problems. For example, if the patients don't know how to care for themselves, we discuss "what the self-care deficit is; what the importance of taking bath is." Usually, we work directly; we bath the patients (N4: p.2).

SOPs available for the nurses at the RSMM are determined by the hospital and signed by the director. They include working time, uniforms, and their job descriptions. Everything that is done by a nurse at the hospital must be related to the standards of nursing care that have been made and legalized by the hospital. These SOPs are analyzed and evaluated by hospital management regularly.

Yes, work standards for the nurse have been determined by the hospital from discipline to working time, uniforms, etc. They determine their jobs. There is a work standard. It means that everything that is done by a nurse at the hospital must be related to the standard of care that has been made ... in this case, the SOPs. These SOPs have been legalized by the hospital and these SOPs are signed by the director ... These SOPs are requested by each profession, each unit; they are analyzed by the management and finally they are signed (N15: p.2).

MPKP (Professional Nursing Practice Model)

SOPs provide a method of nursing care that is called the MPKP (Professional Nursing Practice Model). MPKP includes NCP [nursing care plans] or SP [standards of practice]

related to patients' problems. MPKP is the way to understand how the whole nursing care process occurs.

In this Dewi Amba (a ward), we use a method that is called MPKP. In the near future, it will be changed to SP2KP [standards of professional nursing practice]. Well, here we interact with the patients from the morning until afternoon by using standards. Yes, it is SOP ... it includes NCP [nursing care plans] or what we call SP [standards of practice]. All are related to the patients' problems, we have the SP. For example, patients with hallucinations, we have 4 SPs. Patients with RPK [risk of violence], we have 5 SPs. So, we use those standards to interact with the patients (N6: p.1-2).

Although nurses have worked based on these SOPs, there is still a lack of standardized procedures, norms, and routines in a nursing care method. For example, one nurse indicates that SOPs are often not implemented in the delivery of nursing care, due to different professional abilities.

We work based on these SOPs. [For example, nurses often encourage patients to socialize with others.] However, the evaluation (of socialization) should be ... linked to an appropriate SOP or standard; which one can be implemented. And then it can be supervised and so on. We then, in a specific period of time, make evaluation [about the intensity or continuity of this socialization] (N1: p.1-2).

Nursing Staffing

At the RSMM, nursing staffing is used by hospital management as the process of acquiring, deploying, and retaining a workforce of sufficient quantity and quality to create positive impacts on the hospital's effectiveness. Staffing includes human resource planning to identify what the hospital requires in terms of the numbers of nurses needed. Selection and assessment methods are used to identify the suitable nurse candidate to work in the RSMM.

Shifting or Division of Tasks

Nursing managers are primarily responsible for patient care in their sections of the

hospital. They shift the nurses among the various wards and divide tasks among staff based on a team system model of care. Nurses give report (the operant process) to their replacements on the next shift, discussing special cases or particular conditions, for example, patients who over the past eight hours had developed a condition needing treatment by other professionals.

As the head of this ward, I have my own *Tupoksi* [main staffing tasks]. Team leaders have their own tasks. Other nurses have also their tasks. In the morning, we do operant ... After the operant, there is a preconference to discuss all important cases before we go round to the patients. A ward leader has a duty to arrange all patient care in the ward – nurse staffing, administration and all patient care. As the ward leader, I also coordinate and report to the head of the installation unit [pharmacy unit] ... it will be mediated by supervisor, like that. Structurally, I report to the head of the institution [RSMM] related to nursing. My team leaders work together with other nurses to care for the patients. They [team leaders] arrange nurses [in teams] because here, we use the team system. Therefore, they manage patients ... They can do nursing care from assessing to implementing and performing evaluations with the standards available (N7: p.2-3).

Nursing Process

In the RSMM, the nursing process is a goal-oriented method of caring that provides a framework for nursing care in the hospital. The nursing process involves four major steps: assessing, diagnosing the problem, planning and implementation, and evaluating.

Nursing Assessment

The patient's assessment is based on the SOPs. At the assessment stage, nurses try to establish a therapeutic relationship to identify the patient's actual or potential nursing problems. The nurses assess the patients' overall health, as well as the symptoms of their present illness and its current management. Assessing cognitive function, checking for hallucinations and delusions, measuring concentration levels, and inquiring into the client's hobbies and interests constitute an intellectual health assessment. Emotional health is

assessed by observing and inquiring how the client feels and what he does in response to these feelings. The psychological examination includes the client's perceptions, religion, and beliefs system. A physical examination is also a part of a nursing assessment.

Usually, we make a direct assessment ... We try to establish a trust relationship with the patients. ... [To do this], we say hello and introduce ourselves, etc. Then, we analyze. If they seem ok [cooperative], then, we try to communicate. We also ask them to talk to us. From this, we can collect much data. However, if their behaviour is ok and they are quiet or calm but their cognition is still difficult, we can postpone our interview. Then, we deliver him to the next shift [with the statement] that "this patient ... needs the assessment to be continued (N1: p.4).

Nursing Diagnosis

The nursing diagnosis is part of the nursing process. It is developed based on data obtained during the nursing assessment. Nursing diagnoses are clinical judgments about a patient, family, or community experiences or responses to a patient's health problems. It is also related to the patients' life processes. An actual nursing diagnosis presents a problem response at the time of assessment. Nurses at the RSMM Bogor use the NANDA (North American Nursing Diagnosis). Recently, nurses at the hospital focused on nine mental health nursing diagnoses, therapeutic communication, and individual coping.

Nursing Planning and Implementation

At the RSMM, the mental health nursing plan (NCP) consists of nursing assessment, nursing diagnosis, nursing interventions, and expected outcomes. The nurse addresses each of the problems identified in the diagnosing phase. When there are several nursing diagnoses to be addressed, the nurses will prioritize which diagnoses will receive the most attention first. Priority of nursing diagnoses for each patient is based on severity and the risk of serious harm. The nurses implement the nursing care plan (NCP), performing interventions that were selected to help meet the patient's outcomes. Implementation of nursing care at

RSMM is based on SOPs standards and standard of mental health intervention nursing criteria. For example, patients with hallucinations are taught how to counter them.

There are schedules for [patients'] activities. For example, for hallucinations, they have a schedule of their activities. The SP3 hallucination is to make a schedule of daily activities. Every time we do an intervention, we put it in the daily activities schedule. For example, for hallucinations ... patients are taught how to refuse these false voices. They want to learn; how many times a day, for example, three times a day, what time? We write in the schedule so that they wake up in the morning, take a bath. We have trained them to take a bath. Then, if they want to pray, please, go ahead. They have been trained before; then, they are put in their daily activity schedule (N4: 2-3).

Patients' Support and Motivation

In their clinical practice, nurses also provide patient motivation. Patients can be unmotivated partly through their own personality but also by other social factors. Often the nurses have to direct everything a patient does during his or her day.

From the morning shower on, we start motivating him. If the motivation is not working, we bathe him. To change his clothes he also often needs total direction [laughs]. Sometimes we do [activities related to daily living]. Everything is done with direction (N2: p.2).

Some nurses see motivation as more related to daily activities and physical support, while others see how it can provide emotional support.

Yes, when they express their feelings ... just to listen to them, provides an opportunity for them to express their problem so that they may be solved. People with mental illness need assistance ... so, they need help, have needs. Therapy needs for sure. Then, assistance from their family ... [They need] family members to understand, listen more to the patients. Therapy needs are from therapists, from us, people who are knowledgeable. The main need is family support. For example, he needs to be listened to, understood; also, he needs attention, affection so that he isn't isolated. What is it called? Acceptance, like that ... appreciation too, appreciation, actually. They feel that they are appreciated; although they are the patients, they are human beings too, [and they] like that, appreciation. They need appreciation from their family, society, all these are assets (N4: p.12-13).

Patients' Self-actualization

At the RSMM, nursing interventions are based on a self-actualization model, described by Abraham Maslow as the final level of psychological development when all the basic needs of patients – food, shelter, warmth, security, sense of belongingness, etc. – have been met.

It is about Maslow [Maslow's hierarchy of needs] ... clothing, food, and housing. Regarding self-actualization, some people with a mental illness want [to reach a level of] self-actualization. The most important is self-appreciation, actualization. It is sad when he is labelled a mentally ill person and a useless person (N3: p.10).

Patients' Socialization

Nurses realize that socialization is a very important factor in the patient-nurse relationship. They understand that patients feel more relaxed and confident when they have the ability to share and communicate with a caregiver. Nurses who are more involved in a patient's life will encourage him or her to be more socially active, helping the patient to resume independent living. Patients who are not socially active miss much important information about their condition.

Involve them directly ... direct involvement. So, the point is that they are involved ... they want to express [feelings]. Also, if we are empathetic, they will also express [feelings] ... We say "please sir, I am ready to hear you." Like that. So we always offer ... whenever ... we must have a commitment to be ready to help. "If you want to express your feelings, please, I am ready to help you." Here, in his hospital, I do similar sir. (N4: p.13-14).

Nursing Evaluation

Nurses evaluate the progress of their nursing care outcomes that are based on previous phases of the nursing care plans. If progress towards the goal is slow, or if regression has occurred, the nurses change their plan of care. New problems may be identified at this stage, and thus the process will start all over again.

Inter-Professional Care (Collaboration)

Sometimes, nurses collaborate with other healthcare professionals. The RSMM has an inter-professional model of patient care to provide comprehensive health care services.

We coordinate with other health teams. For example, a patient is irritable. Sure, we collaborate with the medical team. Maybe the therapy is revisited, or psychopharmacology therapy is added, or injection therapy. Nutrition ... of course with nutrition; with the laboratory, if we find the patient's physical symptoms, we collaborate with the doctor. Also, collaboration with other [members of the] healthcare team, for example, laboratory [technicians], x-ray technicians, etc. (N10: p.4).

Patients' Satisfaction

The nurses believe that the SOPs are useful in their nursing care and that care is now much better. Some patient participants like the nursing care they have received at the RSMM, feeling that nurses give them proper attention and attend to their needs.

A lot sir ... For example, their affection, nursing care, the ways to appreciate me, the ways to communicate with me, are all excellent. During my time here in this Yudistira and in Gatot Kaca wards, all nurses and other staff are top-notch. They know what the patients need. They know what I need. Therefore, living here is similar to living with my family. I don't like to be at home or in the village. I like it here more. Here, the patients' solidarity is high sir. I am valued by the nurse. Although I have a mental illness, I am never called a "crazy." Although I am not healthy, they never say to me that I am not healthy. They say that I am still a human being. I like it here. So, I have high spirits again. My life is here. When I am out in society again, maybe I will die. Yes ... It is better here sir (P1: p.7-8).

Others are less happy, complaining that some nurses are careless and some still judge them.

I did learn here; [I learned to] inhale air, scold the voices, take medicine regularly, communicate, do activities. I get many things from here. Treatment is not bad here sir. It is good but ... Sorry, sometimes some nurses are good and some are careless. If I am given food I don't want, they just force me to eat, like that (P11: p.12).

Patients Discharge

Patient discharges are recommended by the nurses in collaboration with the medical doctors. A recommendation to go home is given if the medical personnel believe that the patient has the ability to live outside the hospital, if he or she has the knowledge about their medications and the willingness to take them – what is called the patient ability method.

For patients to go home, in this ward especially, we implement the patients' abilities method. [They must have minimal] abilities ... for example, patients with hallucinations ... [their] hallucinations can't exist anymore. Or, they know how to handle their hallucinations. In addition, they have a willingness to take their medicines. Also, they must know about their medicines. What are their medicines? When must they take their medicines? In addition, the nurse here will recommend that the patients are ok to go home. Or the patients are allowed to go home by their medical doctor. (N6: p.4-5).

Then the family is contacted.

“Doctor,” He is ok; he could be taken to go home.”... like that ... We ask for acc [permission]; if the doctor has said “ ohhhh [okay] yes, ok”... then, he/she writes in a medical resume book, acc to go home when the family member comes, for example, when a family member comes ... ohhh sir, he is good, he has already been acc by the doctor to go home, it is better if he goes back home; like that. If the family rarely comes, we call them to come. Then, the procedure when the family does come, we do health education. The first, we ask the family, are they ready or not to take the patient home? The patient's condition is like this. If they agree, we arrange everything, they are helped ... administration; don't forget our health education, then provide medicines to go home, explain how to control [the patient]. It is like that (N9: p.3).

Patients can be forced to go home even if family members do not want to come to get them – a practice called patient dropping. One nurse participant indicates that dropping is done by nurses if the patient is able to be cared for at home, but family and relatives will not voluntarily make a decision to accept the patient. The hospital agrees to provide transportation and pay the staff involved. If the family does not agree to this, it should be made quite clear in writing why they were unable to provide these services.

Some families don't want to come. They are contacted; usually there are

phone numbers available, but when we contact them they don't pick up the phone. Therefore, we do a home visit. Also, we do dropping ... when the family refuses to allow the patient to go home. So ... we bring the patient home from the hospital. (N11: 3).

4.1.5. Family Care

As the nurses admit, families feel burdened and are unable to cope with an ill person who must be constantly cared for. Shifting the care of mentally ill patients from the hospital to home has only increased the burden.

[Mental illness places a] burden or [causes a] problem for a family [although] at the beginning of [the] mental illness, it is ok; families can still accept the patients. But when it goes on for a long time, the family begins to feel hopeless etc. This happens a lot. However, some are still able to accept ... that I have seen (N1: p.7).

Family members must deal with crises, encourage care and treatment, secure housing, and monitor symptoms and medications, but they often do not receive the right information or resources. They are not adequately regarded for their knowledge of their family member and for their potential contribution to mental health care.

Because of the family's inability to care for the patient for many reasons, they spend only a week at home. They are longer at the hospital than at home ... That is our barrier because most of the families are unable to care for the patients. Although we conduct a family counseling program, or individual program, the families find it difficult to come, I believe, not only because of their shame, but also [because] they are afraid to take the patient home. However, with each family, we have a commitment that every three months, the patients must go home (N8: p.5).

Family Rejection and Abandonment

Rejecting the patient and denying his or her mental illness can happen even after the first hospitalization, leading to reduced participation in treatment and lessening the chances of recovery. It prevents the patient's family accepting their relative's illness and taking responsibility for them.

Because most patients ... especially, patients in the third class; the time comes for them to go home. Their doctors allow it and we also have contacted their families. It will take a long time to pick up the patients. Yes, it seems, as far as we know, [the families] are happy – happy if their family members are still in the hospital. That is our understanding. Maybe they think that [it is] better if their family member stays here, [because] they don't like to take care of them at home. Um um ... Better if their children, their family members stay at the hospital, especially for the low economic class families (N2: p.9).

Some patients have been abandoned by their family in the hospital; they are deserted by those who have the responsibility to provide for their care or who have physical custody of them.

Yes. Finally, I was brought here by my brother, M. But he does not come here anymore until now. My brother and my family threw me in here. They are not responsible [people] ... I want go home [because I am healthy] ... That's it, my family is not responsible (P2: p.2-3).

Another patient mentions that for several years he has never been visited by his son and daughter. Even well-educated families can still abandon family members.

I have two children, a boy and a girl. One graduated from the US – [from] Seattle, Washington. He just came back home ... My wife died in 2000. My daughter does not want to visit me either. No, they don't ... I am alone. My children don't want to visit me. It has been about 3 to 5 years; my son doesn't want to visit. When my brother died, [my son] was in Jakarta but he did not want to visit me ... (P12: p.1).

It is particularly hard to get families to pick up their old patients, or those who have spent a long time in hospital. Although the family is willing to look after patients at the onset of their illness, feelings of hopelessness and even indifference begin to set in if they do not get better quickly. Patients hospitalized over the long term often leave family members feeling trapped and exhausted by the stress of the daily struggle to care for them; taking the person out for a drive, getting the person to an appointment, bringing in a meal to the hospital, offering to spend time with the patient, etc.

Especially for long time patients, for example, [those who have been] many years here, [it is difficult to get them to take their relatives home.] Because they assume that at home, the patients will annoy them. They will annoy their family's activities. Yes, one of the problems is one of annoyance. Besides that there is a feeling of being ashamed and there is stigma about mental illness (N6: p.5).

4.1.6. Community Facilities and Services

Home Visiting Program

At the RSMM, the nurses visit the homes of patients whose families have never been to the hospital to see them. They offer a family-focused service to the parents and other family members, addressing issues related to basic mental health care, good parenting practices, safe home environments, and access to mental health services.

Home visits ... Umm umm. In this Dewi Amba ward, with children and teenager patients, we do visit the family, but only for patients who haven't been visited by their family. Yes, never been visited. However, if family members visit the patients here routinely, we don't do home visits anymore (N6: p.2).

During the home visit, the nurses try to determine why the family is not ready yet to accept the patient back, and they will try to make preparations for discharge.

It means that ... we see what the barrier is against a patient not going home yet, right? Then, we do a home visit. We coordinate [with the family], usually ... for a patient's discharge planning. We explore the family's ability, again. What the barriers are ... Why the family is not ready yet to accept the patient at home. (N1: p.6).

Mental Health Foundations or Institutions

Outside the hospital, there are several services for the mentally ill. Some doctor practitioners are available for the patients who need medical treatment; however, not every patient can afford the fees since they are mostly not covered by health insurance such as Jamkesmas or Jamkesda. One patient participant could afford to have a doctor.

To adapt to this problem, I will visit a psychiatrist. My doctor is doctor IM.

He is a psychiatrist in Rawamangun. Doctor P is in Bogor. His home is in Depok, probably; I don't know. With my mental illness outside [the hospital], in Bogor or in Jakarta, I go to my doctor (P9: p.7).

Some, primarily the rich, will continue treatment at foundations or private institutions, managed by nurses and doctors, but these are limited and only available in the larger cities such as Jakarta and Bogor. One patient mentions that she has a private psychiatrist who has a foundation where patients can go to have psychiatric treatment.

Before, I have been with professor K. Professor K was a teacher of professor DH who has a foundation in Menteng. Menteng is in Kebayoran Blok M [a place in south Jakarta] (P7: p.2).

As one nurse participant lamented, to her knowledge many discharged patients end up on the streets (N5: p.4). Another nurse agrees – although there is more understanding of mental illness in the community, more help is still needed.

Now, the community has begun to understand. Many places ... everywhere. But ... the problem for us now is that institutions or foundations outside to care for the sufferers are very limited (N3: p.6).

Puskesmas (Public Health Centers)

One of the community services available for patients with mental illness are the *Puskesmas* (public health centers). *Puskesmas* are government-mandated community health clinics located across Indonesia and overseen by the Ministry of Health. A *Puskesmas* serves the residents of a *Kelurahan* (neighborhood) and surrounding area. It also provides early diagnoses, basic medical treatment, and nursing care. If necessary all *Puskesmas* provide referrals, laboratory services, counseling, and a rehabilitation program. They are considered the front-line treatment centres for patients suffering from a mental illness. Outpatients from the RSMH are referred back to a *Puskesmas*.

We have a community ... a referral *Puskesmas* [public health center] for patients with mental illness. Then we ask the family to bring the patients

there. All Puskesmas provide healthcare for patients who suffer from mental illness (N6: p.11).

Posyandu (Integrated Health Care – IHC)

A *Posyandu* (Integrated Health Care or IHC) is another service available for patients in a community. An IHC is a basic community self-help activity organized by and for the people, assisted by healthcare workers and community health personnel. The person in charge is the village head. The IHC helps to integrate healthcare between the hospitals and communities. According to one nurse participant,

The best nursing care [is in the] *Posyandu* in the community. If in Bogor, the *Posyandu* [can help provide information on mental illness to all] [The mentally ill] are provided medicines ... [and] if their families are supportive, we provide health education about social isolation, violent behaviours, and hallucinations. These are all provided (N8: p.13).

Internet-Based Community Services

There is also an internet-based community service managed by some former mentally ill patients. However, it is only available for patients who suffer from schizophrenia in big cities such as Bogor and Jakarta. It is not available in remote areas or villages.

In Indonesia, there is a schizophrenia community now. I love to provide support for them, for the families who have members suffering from this mental illness. I never get bored of reminding them to “Please, click on Google about schizophrenia.” You will find it. Its secretary is a former patient here. His name is L. He is the secretary in this schizophrenia community. These are people who have jobs. So, people with this mental illness ... They have their own community. In this community, the patients gather together. In Indonesia, it is really good. (N12: p.16).

Community Mental Health Nursing (CMHN) Care

Community Mental Health Nursing (CMHN) supports people with mental illness in a community setting, with the goal of providing the most appropriate services to the patient, whether admitting them to a psychiatric ward of a general hospital, enrolling them in a

Puskesmas or self-help support group, or providing supported housing with full or partial supervision. Community mental health nursing services are provided by mental health nurses, including specialized teams trained to detect psychoses early, and those trained in assertive community treatment (ACT), a new legal power that has developed in Indonesia to ensure compliance with the treatment of individuals living in the community.

The ACT program is a model of mental health services delivery that provides comprehensive, individualized care at the community level, providing mentally ill patients with treatment, rehabilitative, and support services in order to improve their ability to live independently. It involves periodic visits for consultation at community-based outpatient facilities. ACT is a partnership program between the RSMM Hospital, the community health nurses, and the Puskesmas. Healthcare providers visit outpatients every one to two weeks, and they can refer patients to psychotherapy or back to the hospital if the need arises.

In our place, there is an assertive community treatment (ACT) program. Actually, this program has just been adopted by our hospital to bridge most ex-patients from this hospital who go back to the community. We must follow the development of these patients in the community ... whether they are in accordance with our expectations or not ... Actually, the main centre of this community assertive treatment program is the Puskesmas, because the patients who have been hospitalized will return there ... our program in the community assertive treatment is not only for ex-hospital patients but also we pick up the new patients in the community who are not reached by healthcare facilities, and who cannot use healthcare services or the hospital for medication and who cannot do self-care ... Usually, our friends in the public health center have found the cases. For mental health patients; for example, whom they cannot manage, our team will come. Usually, there, we do both nursing and medical approaches. Nursing care is a nursing diagnosis approach. There, treatments are for the patients plus their family and community. We provide positive images to the community, especially to religious leaders, about how to care for and how to treat the patients around them (P.3-4).

4.1.7. Community Care

Social Participation

Social participation contributes to health by providing a sense of meaning in people's lives as well as increasing access to social support measures. If people in the community provide care for the mentally ill, the social relationships formed can lead to fulfilling attachments and feelings of social approval and belongingness. Social participation provides social identity and security for the patients. Such social relationships are useful because they are helpful in developing self-efficacy. However, this kind of social care in Indonesian communities is very limited.

So far, community support can be found only in areas reached by people who are concerned with the problems of mental illness. For example, in one village, there is a cadre of mental health workers under a mental health facility. ... But in my area ... there is no attention to them. In my experience, because they know that I work in a mental hospital, if someone is stressed or suffers from mental illness, they will come to me. "Sister, how about this? My brother is confused, he is violent, this, this." As a part of the community, in order to help them, I tell them the way. I only can tell them about the way to have treatment without paying. If there is direct attention from [mental health workers] in my community, I have never heard (N9: p.8).

Community Burden

According to some nurse participants, a lack of social acceptance for mentally ill people has resulted from the significant financial burden they have placed on communities.

For 30 years ... if I compare the first time I worked in psychiatry to recent conditions [although I have not conducted any] research there is no a significant difference or change between before and now in how mentally ill patients are accepted. They consider that the patients are a tremendous burden for them (N1: p.6).

Lack of Social Care

As some nurses point out, no levels of society pay attention to the mentally ill and many of these people end up on the streets.

In my opinion, generally, people who suffer from mental illness in our societies are very miserable. Yes, very sad. We can see that ... why do I say miserable? Because many mentally ill sufferers are still on the streets and nobody cares about them. They are not cared for by their families. In addition, even the government isn't involved in caring about them. Miserable – they should have appropriate care. But they do not have it ... they are brought to the hospital but they do not get their rights appropriately. Their condition is miserable, very sad. Therefore, because of having mental illness, they have physical illness too (N6: p.6).

Many community members will not interact with mentally ill people.

Our societies still lack care ... less attention is given for patients with mental illness ... They are just ignored, like that ... I am sure, if [there are] 10 people with mental illness, only 1 or 2 people will want to say hello or interact with them (N7: p.13).

4.1.8. Government Care

Government Health Insurance for Poor People

Since 2005, the Ministry of Health of Indonesia has implemented a health insurance program for people who have health problems. Initially, it was known as the Health Security for the Poor (JPKMM) or Health Insurance for the Poor. In 2008, the name changed to the Health Insurance Scheme for the Poor (*Jamkesmas*). The program improves access to quality health services so that users can achieve optimal health effectively and efficiently. Another form of health insurance provided by the government is called *Jamkesda*, which provides payment assistance programs to guarantee the cost of medical services provided by local government districts to the regional community.

[For patients] at the middle to low economic level now, our government [automatically] provides some insurance, for example, *Jamkesda* ... However, is there willingness for the family to find insurance for the patients to be

brought to the hospital? (N5: p.5).

A nurse participant states that these forms of health insurance for poor community members indicate government support. According to the IBP Indonesia Core Team (2012), Jamkesmas is a national program providing financial protection with respect to the health care costs for the poor and near-poor population in Indonesia. The objectives of the program are to provide easy access to all members to the Jamkesmas health service providers network and to promote standardized health care in order to prevent excessive service that may create an additional burden of costs. Jamkesda is a local government response to the need to provide health care insurance for citizens, particularly for poor people at the provincial level. The Indonesian constitution has allowed local governments to establish their own agencies to manage the health insurance scheme in each local province.

[...] It is a kind of support. So, one of the ways the government pays attention is by providing the Jamkesmas [community health insurance] card and Jamkesda [local health insurance]. It is a kind of government attention ... It is a health insurance scheme for poor community members (N10: p.8).

Lack of Government Care and Attention

However, Indonesian mental health services are currently fragmented and many people do not receive appropriate treatment as a result. The lack of government attention, combined with other factors like stigma, have isolated patients with mental illness. One patient argues that the government needs to focus on patients with mental illness.

[...] other than social attention and treatment, attention from government is 0%. ... There should be some places for treatment of the patients in the community, not just to wait for their families to come [to the hospital] ... Generally, [patients] have families but when they leave to go home, some ... do not know where to go for help. (P14: p.14).

According to one nurse participant, the government should ensure access to the right combination of services, treatments, and support for the mentally ill to prevent

the “revolving door” from hospital to homelessness.

Our country has a department of social governmental service, right. They must be responsible and concerned about that. However, sometimes, I see that patients are homeless. We care for them here until their condition is good. Then, they are taken back home because their health insurance expires. But, I see that he is homeless again in the mall, homeless again ... a beggar again. Has he been taken from the hospital to continue his treatment by social service or is he just taken to be released again? Therefore, I am confused ... Actually, if there is a good system, he would be better again ... he would not be like that again. (N9: p.7).

As one patient states, many are still on the street because the government does not pay enough attention to them to encourage treatment in mental hospitals. The government still lacks care.

Why doesn't the government take them and put them here ... [They] should be brought here, to have treatment. It would be good if they were here, or in Bandung. They are not cared for by our government (P14: p.4-5).

4.2. CATEGORY 2: VIOLENCE

The focus of this section is to discuss the relationship between mental illness and violence. Violent behaviour, whether physical or psychological, can cause people to injure themselves, other people, or objects in their environment. Those with a greater tendency towards violence often feel threatened or manipulated by outside forces. Not surprisingly, many patient participants stated that violence stemmed from the treatment that they had received from others. Mental healthcare settings are considered high-risk work sites. The data analysis indicates that violence is a common occurrence and is encountered in some fashion not only by the mentally ill patients who participated in this study but also by medical personnel, family members, community residents, and government officers. The following section discusses the forms of both physical and psychological violence in order to understand the perpetrators, the victims, and the effects of violence.

4.2.1. Patients' Violence

Violence to self (self-harm)

Suicidal ideation means that the patient wishes to die and intends to hurt him or herself on purpose. One patient describes the feelings of social isolation that led to his preoccupation with self-harm.

Very strange sir, very strange ... sometimes I cannot control myself until I have a suicidal ideation. I have tried to kill myself three times by drinking poison but I don't die ... With this mental illness, I feel low self-confidence. I feel confused also; with other people, I am afraid. I am afraid to see other people (P1: p.3).

The patient understands his problems with his family and community trigger his suicidal thoughts, but he feels powerless because he knows that his religious beliefs do not allow for suicide.

I have tried many times to commit suicide but Allah does not allow me to die. I am not allowed to commit suicide. I have to live; although I am not supported by my family, I must remain alive (P1: p.7).

Violence to others

Patients also admit that they have been violent to their family members or relatives, and are often admitted to hospital because of this behaviour.

Okay, I am the second of five brothers and sisters. I am the most difficult and am a burden on my family. Because of difficulty in my life, I have to be here. My brain has many problems. Therefore, I was angry and violent at home [and] then, I was brought to this ward (P1: p.1).

Another patient participant mentions that his problems at home have to do with his mother; he is angry because she will not give him the money he wants.

Because I am RPK [violent]. And then, I sold my hand phone, my television, DVD and ... Cheap, cheapest ... Cheap. The hand phone's price was 3 million, but I only sold it for 300 thousand because I needed money to buy food, to buy cigarettes. Yes, I am angry at home because my mother does not give me money. So, I am angry with them and I hit my mother (P15: p.2).

Patients who are violent are sometimes hidden by their families, leaving them all isolated and marginalized in their communities. As one nurse states:

L [a friend] has a family member with mental illness; if [the patient] is violent, he destroys the roof, home, etc. So the family of my friend is secretive and hides him. [They are] rarely [invited to community] parties. So, they are isolated. They are marginalized (N11: p.9).

Community members also experience patients' violent behaviours, helping to explain why patients are rejected and isolated.

I was brought here because I smashed and broke a person's home sir ... Yes. I was angry at home. However, I wasn't angry at my work. I was annoyed by [his neighbour] using a magic... Yes, he used a magic 'Mulut Keampuhan [a kind of Indonesian magic]' sir. I don't like it ... This Mulut Keampuhan was from his grandfather. His mouth needs to be kept silent ... "not to talk bad things'. Just talk good things ... Yes, it made me angry sir (P11: p.2).

Another patient explains:

Then, my brain is messy ... I am angry at home. I broke my glasses at home. I challenge the headman [head of a district] and the head of RT [a local neighborhood involving several houses] to fight with me. They are my family members. I bring a cleaver and a *clurit* [big chopping knife] to kill these people. I say: "what do you want? ... If you are all the *jawara* [champion], let's fight." They are not brave. Then, I am attacked by 100 people. Finally, I am brought here ... The head of RT, they were who I would attack ... Then, I was also hit by these people (P1: p.2).

Patients are also violent toward community facilities, destroying things.

I threw the ashtray. The story [is], I lent him 1.5 million. He pays back with installments. A hundred, fifty, my money from BJB [Bank of West Java] is over... I am angry; I cannot control myself anymore. I [am] angry, like that... then, I am brought here (P13: p.4)

4.2.2. Violence Experienced by Patients

Restrictive measures: *Pasung* and *seklusi* (restraint and seclusion)

People with mental illness are more likely to be victims of violence. Research reveals that *pasung* and *seklusi* are still being used as tools in Indonesia to deal with mentally ill

patients. Pasung is a term meaning restraint, a practice of rendering people harmless, helpless, or keeping them held captive. Afraid of both the shame of mental illness and the potential for violence, families tie their relatives to a large pillar, chain or handcuff them, or put them in *balok*, in which patients' feet are inserted into wooden shocks (beams) that are hollowed out enough just to fit the size of the feet. Pasung is said to minimize patients' violent behaviour. Seclusion, or *seklusi*, can take several forms: families may hold their mentally ill relatives in solitary rooms in homes, cage them like animals, or socially isolate them in the jungle. Patients reveal their experiences with *pasung*.

I was tied, chained in the backyard, but without sunshine etc. It was done by both family and friends. My friends were there (P14: p.10-11).

The family and community member brought me here [hospital]. First, I was handcuffed. In addition, my feet were restrained for 15 days. Then, the local health [person] came to my home. Actually, they were from local health and the police and a soldier. If I hadn't been released by the police, the soldier and the local health, I am sure that I would have been restrained forever. Yes, it happens. People do crimes such as pasung ... [they] take away my rights; all these are worse. Then, they tie me, like that sir. (P14: p.3-4).

Some nurse participants indicate that patients are tied, chained, or put in wooden beams.

Yes, it is suffering. Many times we accept patients who have been restrained ... sufferers are tied, chained, put in wooden beams; but, there are also pasung where the sufferers are put in a small room and given food once a day. Some of these patients cannot walk. They are thin and malnourished. [They can hardly talk]. Their families are rich; if they want to bring the patients [to a hospital], I am sure that they have money, in my opinion (N13: p.14).

Patients are sometimes placed into a small room.

Yes. He is not allowed to go out from home. Some people are not only restrained, but they are locked in a room. I have heard their family's story. It is similar to the jail. He is just provided a window. If he wants to eat, the window is opened, and then he gets the food to eat. He doesn't take a bath. Nothing is done for him. I have heard this story ... "Yes, because it will be a problem for me, nurse, if he was violent, we don't know what to do, if he is released, he must be violent." They say that. He is only given food once a week; or once in two weeks to be cleaned; it is because of the shame of the

family (N9: p.12).

Nurse participants are aware and believe that pasung and seklusi are happening in families and communities, and believe that there is a lack of knowledge to care for patients with a mental illness.

Yes, [there is] much information now that the patients are restrained. Sometimes, here, we also admit some patients who have a history of pasung at home ... because they are violent, because they annoy society. Maybe [they] don't know how to care for people with mental illness like that. It is reasonable too, right? Probably it is better for them to save other people than to care for a mentally ill person... (N9: p.5-6).

One nurse states that he has a friend whose family looks after him well because they are educated. However, he acknowledges that this kind of family is very rare.

I have a friend who has a family member who suffers from [mental illness], he can survive; fight, because he has knowledge. However, people like him are very rare. (N1: p.8).

Another nurse explains that some patients, who have become stressed from working abroad, are been caged by their families when they return.

They are tied to a big pillar. Also, some are put in goat or chicken cages. Therefore, they are caged similar to a goat. [The patient] has to defecate there, eat there, like an animal. This is not just a story but I see it directly; [I am] a witness to this condition. Six patients have been brought [to the RSMM hospital]... Yes, some of them. [This area sends many workers to work] in West Java. So they are stressed because they work there, in Saudi Arabia. They are stressed and return to Indonesia. They are caged by their family (N15: p.18-19).

Another model of seclusion is social isolation where the patient is put into the jungle by his or her family members. One nurse participant believes that this kind of seclusion is considered a human rights violation.

The patient who is put in the Sibolga jungle is accompanied by his family. At the jungle's gate, he is released, similar to a beast. He is put in the jungle and he will live alone, as he can. Either he finds food or not. So, in the jungle, I see some people ... there is a woman put there because she has indicated she

is a mentally ill person by her being angry, talking to herself, hallucinating; she is put in the jungle ... She enters herself; she isn't given food and drink. Is it included as a HAM [human rights violation] or not? Actually, is it considered HAM (N3: p.7).

As one nurse points out, families are often forced by their communities to do something about their mentally ill relations or they experience violence at the hands of their neighbours.

I have worked in ICU, where a patient was restrained by his community members. The headman did the pasung. Many of these things happened in Banten village, Tangerang. In Tangerang villages, many people are restrained, put in wooden beams, put in rooms with only food and drink. Sometimes, they sleep in the cemetery, restrained, chained. I have their photos. These societies don't understand because [patients] have destroyed the community before; they have [gone on a rampage], destroyed peoples' assets such as their musholla [small mosque], mosque, and the market. Then, they can hurt their community members, they can also become killers. Therefore, they are considered dangerous people. Many patients with mental illness are like that ... Usually, if the family members have restrained their relatives, actually, deep in their heart when they are asked, they feel pity; it happens because they are obligated by their society, because [patients] disturb other people ... Yes, communities ask for them to be restrained] (N4: p.3-5).

Another patient participant mentions that he was attacked by people.

For example, I have fought with some people. I was beaten by people in my community. I fought with 100 people. Because they think that I am harmful; harmful for the community members ... Yes, I have a mental illness problem (P1: p.10).

One patient was hit with bamboo until his body became swollen and bruised. This kind of physical abuse makes the patient afraid.

Under my bed, there was incense, this incense was burned. I was given many things ... After that I was hit by using bamboo. Finally, I run away. Therefore, it is dark blue [shows her skin]. I was just in the room. I was scared (P3: p.10).

Patients are aware that pasung is maltreatment or even a crime against the mentally ill, and that a person's rights are taken away when it happens.

Mentally ill people are not bad at all. Basically, they are not bad. However, people commit crimes against them ... crimes such as pasung [that are] maltreatment. They take away my rights. I was restrained because why? I was restrained not for recovery. But, I was restrained to make me "crazy." It is more painful, right. (P14: p.3-4).

Psychological Violence

According to some nurses, family members also use psychological violence, also considered pasung, toward their relatives who have a mental illness. One form is abandonment or negligence. As already noted, family members sometimes never come to visit patients at the hospital, or refuse to come and get them when they are ready to go home. Others are abandoned even before reaching the hospital.

The patient is isolated; abandoned [and] homeless on the street. Especially, it happens in Bogor that the families bring the sufferers, no one knows from where. After coming to Bogor, the patients are released at the traditional market. Then, social services take them and bring them to this hospital. After their conditions become better here, we ask for their addresses. Then, we make a home visit, and we find their address. We ask the family "why did you do that, "that time he/she was sick therefore we left him/her there." From that, we know that families are ashamed because one of their family members suffers from mental illness (N12: p.15).

Government Violence

Most violence from government, primarily police officers, is related to restraint and seclusion. One patient participant described his detention in a police office. Another was handcuffed by the police because of his violent behaviour.

I am really disappointed with my mother who lied to me ... Yes, I was handcuffed. The police handcuffed me. My mother asked for help from the police to handcuff me. But this handcuff was broken. See this [there are scars in his hands] (P15: p.3).

Violence Involving Medical Personnel

Physical violence against nurses and security guards in hospitals has become an endemic problem. Health care workers, especially mental health nurses, must routinely

handle patients who are delirious, agitated, and even aggressive on psychiatric units.

Also, I came here [to the ward] because I often fight with the [nurses]; I fight with them too. Therefore, I don't feel comfortable... here, at this hospital, twice ... eh three times. I fought because of a problem with water, just a misunderstanding. But I don't want to fight anymore (P1: p.2-3).

But hospital staff often physically abuse patients themselves. Physical violence conducted by nurses is a major issue for the nursing profession in a mental health hospital setting. Both restraint and seclusion are used in the RSMM by the nursing staff.

I have raged. I destroyed ...[unclear]. I was hit at Kresna ward. My head was hit with a folding chair. It was broken [laughs]. Yes, my hands and feet were tied because I was violent continuously. I did not make mistakes but I was handcuffed. When I came again here, I was also handcuffed. There, by the staff in Kresna ward (P2: p.3).

Like that, I mean, I also experienced that by the nurses. I was freezing sir. I was tied, yes. I was tied 7 times ... I was tied ... Only in Kresna was I tied. (P3: p.7).

A violent person, in danger to him or herself or to others, is isolated in a room. It is used as a control strategy in psychiatric treatment settings, although some see it as a form of punishment. While the nurses recognize that this intervention is unpopular, it is sometimes the preferred course of action to prevent prolonged physical intervention. According to several participants who were interviewed, patients are isolated in dark rooms; one states that he feels as oppressed as someone in jail, a situation made even worse because he is not allowed off the ward for walks.

The staff considers crazy people a source of harm, a big disaster and very messy. In addition, they consider that these crazy people are really crazy. Crazy people are not human; they should be abolished, they should be burnt, they should be kicked, and they should be punched, and must be placed in a dark room in Utari (ward). These must be eradicated; therefore I don't want to go to Utari anymore. Doctor Y said "don't go to Utari anymore, Mrs. C." Yes, it happened, I was like a pig being dragged. I remember the staff in Utari. But, there isn't a dark room here. I don't want to move to Utari ward (P9: p.1-0-11).

Some patient participants indicate that being placed in the seclusion room is a traumatic experience. They are forbidden any social activities.

Here [in the hospital] I have been caged. I am not allowed to go for prayer. I cannot go for Friday prayers. I cannot socialize with the community. We need to socialize, right? God says; “socialize with other cultures and other nations” (P2: p.11-12).

Often the security guards and nurses are perceived to work together.

Everything is destroyed. The TV is broken. My friend in Sadewa (ward) has destroyed the TV. Now, he is here, in Kresna (ward) again. The patients are roughly dragged by the security guards; they pull the patients. “Come you,” [they say]. I was also pulled and forced. “Come on you there.” I was pulled. The security guards [were] put on [us]. I don’t like to be treated like that (P2: p.5).

The nurses admit to the practices of restraint and seclusion.

Yes. Some patients who come here are tied. But, they are adult sir. Here at this ward, someone who is tied comes here because he does not eat, [and he has been] hit until swollen. Yes, his body swollen. If a patient has run amok usually he is tied. Many patients are socially isolated, right? They are just mute, usually ... but still in most cases they are tied, on the average. Yes, if at the IGD [emergency unit] (N2: p.5-6).

Another nurse states that most newly admitted patients to the hospital are restrained.

There are two kinds. If patients coming to the hospital are very irritable, some of these patients are tied; moreover, some are handcuffed. If patients come with less irritability, they aren’t tied. So, there are two possibilities [at the RSMM] ... If the patients are in an irritable condition when they come, they are tied. But if they aren’t really irritable, they aren’t tied (by other people). They are brought by family [or] by the police here. Yes, the police ... Like that. If new patients, recently, mostly, they come tied (N6: p.4).

Another manifestation of the dysfunctional anger of nurses in the mental health hospital is verbal abuse. One nurse participant is saddened by colleagues’ attitudes.

Sometimes, I am sad if I see a patient is shouted at, snapped at, for example (cries). However, it is difficult to change that. It isn’t my responsibility alone. I mean ... why are they bitchy with the patient? Other people also see ... Maybe the patient is annoying too. Okay. The most important thing is that I

don't do that (N9: p.10).

4.3. CATEGORY 3: FEAR

Mental illness is often associated with fear of a potential threat from sufferers, commonly called psychophobia. In this study, participants stated that they know that families, community members, and health care workers are afraid of them. This fear of mentally ill people can lead to patients not being referred for appropriate care for their mental or physical needs. Mental illness causes a strain on patients' relationships with others and conjures up fearful emotions.

4.3.1. Fear of the Patients

Fear of treatment modalities

Patients are often afraid of their treatment, especially of the abuse of alternative treatments or traditional medicines. One patient who was brought to a traditional healer had been terrified.

Yes, ummm yes ... it was wrong. In Ngawi [a small county in East Java], I was [there] only three months; it was fearful. I was in a remote area in Java, it was very dark. I was obligated to meet Mr. MA [a traditional healer] ... I was just in one room. I was scared. Mr. MA was there. He was an ex-mental illness sufferer too. He said: "It is a crazy illness. This is a psychopath," he said. I wanted to run, escape. I was really afraid to see his axe. I was so stressed, [it was] a strange treatment (P3: p.10-11).

But patients can also feel traumatized by medical treatment in a hospital. Indonesian communities often force them into going to the hospital if they or their families do not seek help voluntarily. As one patient explains, the local headman arranged to have him admitted.

"You would be picked up to have treatment." They said, "The headman said that"... "Why?" "We were obligated by the headman [to bring you to the hospital). There you will recover quickly," the people said. I was sleeping when I was brought in. I was in my bed. "Why was I brought, I could do it myself." "This afternoon!!!" the person said. When I remember that time, I am so sad, [it was] traumatic [looks sad].....traumatic and sad (P6: p.1).

Patients may fear what will happen to them when they are in the hospital, and as was pointed out in the previous section, they may well experience violence in their dealings with hospital personnel, or be forced into seclusion. They also have real fears that they will be abandoned by their relatives once they enter the institution. There is also an assumption that psychiatric medicines will make them dependent on drugs similar to those who are substance abusers. Family members will often refuse to admit their relatives to the hospital because of this issue, and it is one of the reasons they often try alternative medicines first. Alternative treatment is preferred because they feel that the treatments given there are not harmful and are without chemicals.

In addition, I hear from the family that ... they are afraid. They don't fear the patients but are afraid that the medications will make them dependent, similar to the NAPSA (substance abuse dependence) patients. So, they fear to bring them to the hospital because they are afraid that their family member will be given psychiatric medicine, therefore they feel that it is better to go to alternatives. At these alternatives, they are just given water [for treatment]. By giving them water therapy, there is no effect, right? [But] in taking medical drugs, they fear the chemicals in the medicines. (N4: p.14-15).

Fears of the families

Living in a family in which one member has a mental illness is not only challenging, but has special problems for family members. A common fear experienced by the family is that the patient will be violent. Family members are afraid to deal with the instability or unpredictability of the patient, and believe that their relatives can be dangerous. One patient described the effect his anger had on his family.

Usually, it is about arguments. If I am the loser, then I am violent, angry. [Family members] just want to be safe ... Yes, they just want to be safe. They put me [in hospital]. They will be free and safe. No more religious arguments. Ummmm ... they are family members. I am just to be a patient. If now I am upset, it is [only] human (P5: p 8-9).

Fear that the patient might repeat his or her violent behaviour leaves families feeling uncomfortable in their own neighbourhood.

Yes, it could be shame too, since most of the patients who experience mental illness disturb the society. Generally, male patients disturb their communities and family members don't feel comfortable with their neighbors. Yes, they are. They are afraid if [the patients] act the same again (N11: p.6).

Afraid to be refused in the hospital

Many people, especially in remote areas, fear that their relatives will not be accepted in the hospital and thus choose to restrain them at home.

Many in remote areas consider the patients will not be accepted in the hospital because they have mental illness. [They fear being labelled]. Therefore, they feel it will be better to restrain patients rather than take them to the hospital because it will just be a waste of money; thus [patients] aren't hospitalized, they don't get anything. (N4: p.15).

Nurses understand that caring for someone with a mental illness can be traumatic, especially for those families who have elderly mentally ill patients, because they lack knowledge about what to do when they return home.

[Family members] refuse because [they have] nobody who can care; because they are afraid [and find it] traumatic to have a mentally ill patient. Yes, traumatic. Family members are traumatized, in my opinion. Actually we do have health education for the family about how to care for the patient at home if they come. However, working with the family is limited; it is a problem for us. Generally ... [family members] are afraid. [Chronic patients provide even more of a] barrier to working with the family ... [and the] elderly who have difficult behaviour and [specific needs]. Nursing care is also specific. Therefore, it is difficult (N8: p.7-8).

Fears of the community

Patients with a history of violence also cause fear among community members, who are afraid of being attacked. Some patients understand why they are shunned by former friends and community members.

Friends, I don't have. They are just afraid. They just talk behind [my back]. I

just let it go as long as I am not slapped ... They are afraid of me. They are afraid to argue with me. They are afraid because I am a mentally ill person. Yes, it could be. My arguments aren't accepted; they aren't understood by them. For example, [if] I speak the truth, they should obey me ... I don't mind. It is not a problem as long as they don't hit me (P5: p.9).

As mentioned earlier, many community members believe that mental illness is a communicable disease, and their fear of contagion contributes to a sufferer's isolation.

[People] think that [patients] are sick, not good, [and that their illness] spreads, it is similar to a contagious disease. Similar to a contagious disease ... they must be isolated. The patients must stay away from them [and not] communicate with them (N4: p.11).

4.3.2. Fear of Mental Health Personnel

Fear of mentally ill patients

Staff nurses who work in the mental health facility admitted to psychophobia or fear of their mentally ill patients. Outside the hospital, they are as likely to perceive the mentally ill as dangerous as the rest of the general population. One nurse participant acknowledges that she is brave when at the hospital but afraid when she is out in the community.

I have a neighbor right next to my house who suffers from mental disorders and he has been back and forth to the hospital; goes back home alone many times... I myself [work] with mentally ill patients, feeding and bathing them and so on in the hospital. But outside the hospital, because of the stigma, I feel fear (N2: p.4).

Fear of mental illness

Even some nurses as frontline caregivers still believe that mental illness is a contagious disease; they are not only afraid of the patient but the mental illness itself.

Yes ... When I was still a small girl, I lived in this mental hospital complex. My parents worked here too but they weren't nurses. I was here, at my parents work. I liked to come to my father's ward. If there was a patient who spit, I cried; I was afraid of contamination. Yesterday, there was a student who feared to be contaminated too. She is a nursing student from Palangkaraya, Kalimantan, who is afraid of contamination too. Besides of this fear of

contamination, they are disgusted by mentally ill patients (N4: p.16).

4.4. CATEGORY 4: CONSTRUCTING CURSED CITIZENS

For mentally ill patients, families and relatives, shame is a manifestation of feelings of guilt, embarrassment, disgrace, and unworthiness. Shame is a powerful emotion that can impede the treatment of people with mental illness. Patients feel shame because they are different from "normal" people. They also feel shame because they believe that they are inadequate or because they have not accomplished all that they were supposed to accomplish because of their illness. Families are ashamed of their mentally ill relatives, thinking that they are a disgrace and embarrassment for them. The results of the study indicate that patients are insulted, discredited, rejected, and devalued by people in society.

Patients' feelings

One patient denies that he has a mental illness, and states that he is ashamed to be in hospital with others who are mentally ill. He does not want to be labelled "crazy."

I am put here where it is not for me. I am not a mentally ill person, why can they not differentiate that ... I am ashamed to be seen by the other people. Why can they not differentiate between mental illness and general illness? I am ashamed. Yes ... why '*keder keder*' [crazy people] are put together with me. Why am I put with *keder keder* [crazy people]... I have been here for 28 days. I don't make a mistake. I came [to the RSMM] on 2nd (P6: p.10).

Those who perceive themselves to be members of a stigmatized group, whether it is obvious to those around them or not, often experience psychological distress and many view themselves contemptuously. Another patient indicates that even in at the RSMM hospital, she is looked down on and feels degraded.

Here, I am looked down on, degraded. Here, the nurses are like ... hummhhhh [discredited]. Um um. [They] underestimate their patients. So they do not heal us. Instead, our problem is ... [unclear]. An example, nurse T, she does not help me but she makes problems for me. (P7: p.10).

Some patient participants indicate that they are violent and angry because they are humiliated by other people in their community. *Nyenyek* is a local term of humiliation for people with a mental illness. As one patient recounts:

I was insulted by the children. It was the most painful. Yes ... That time, I had an odd behaviour in front of them. These children were in Cibubur ... [they yelled] “wuiiihhhhh [insult]...hihihihihihi [insult] ... hehehehehehe (laugh)” *nyenyek* [the worst humiliation]. Then, I was angry. *Nyenyek* is an insult in the local language. *Nyenyek* is more painful. Insult is better. *Nyenyek*: “weihhhh ... wuehhhhhhhhh” like that, it is more painful (P10: p. 6-7).

Some nurses recognize this humiliation and believe that patient’s rights as citizens are not recognized.

Yes ... They are discredited. “Ihhhhhh [insult], he is from a mental hospital, don’t get closer.” Or from the children ... “ihhhhhh he is a mentally ill person.” He is insulted; it is a humiliation, right? In addition, their rights as a human are not recognized, it is included in the idea of humiliation too. Yes, right? The patients with mental illness have a right to live and to get help from the country (N15: p.12).

Other kinds of insults include being treated as a social misfit.

Yes, [sufferers] are outcasts ... pushed away. They are given food, “eat this, crazy, nuts.” Sometimes they say: “you are an idiot, you are stupid.” Tongue is full with bad words ... You are “crazy. You are a nut ... it should not be like that (P12: p.12).

Because of both the physical and psychological violence against the mentally ill that is brought about by many harmful assumptions in Indonesian communities, patients feel uncomfortable.

These problems make people suffer from mental illness. I’m happy but [when I experience] disturbing behaviours from outside, I don’t feel comfortable. I am not comfortable. I am not comfortable because of the assumptions of Indonesian people (P1: p.4).

Patients may feel overwhelmed by everything they have experienced, and even if they have their mental illness under control, may no longer cope well with day-to-day life.

Yes, I am nervous of walking around. I am ashamed, anxious and worried; and feel afraid. I am afraid that I am not valued. Yes, I am not valued ... and I am afraid not to be appreciated by other people (P1: p.12-13).

Even when they are released from hospital, many patients understand that it will be difficult for them to be accepted back into their community. They know that they will likely not be accepted.

Without acceptance from family, friends and society; I am [full of] anxiety and worry. In addition, I am really ashamed and angry. Then, I really regret with what I have done (P1: p.11).

They express fears of humiliation and afraid they will be insulted.

No, they aren't. I am scary to them. I have been a brave man before. I have been continuously insulted. This worsens my mental disorder because I am insulted a lot. I am insulted by other people. For example, "you are a crazy person. You are a wrong person. You are not a responsible person"... I am a responsible person. Therefore, I am blank. I am discredited, I am hit so that my brain is blank, angry; I am also possessed by devils. Finally, I came here (P1: p.3-4).

Family feelings of shame

According to many participants, family members find it difficult to ask for help or go to a mental health facility because of feelings of shame. For that reason, patients are often left on their own or ignored, or taken for alternative treatment first. Only when the patient's condition worsens does the family begin to search for other forms of healthcare.

After they are battered in alternatives, they search for information about health care facilities. They avoid healthcare facilities. They tend to use spiritual treatments first ... It is about feeling ashamed. They feel better about bringing the patient to alternative treatments because they are ashamed. When they have no choice, then they bring [the patient] to psychiatric facilities. Yes, many times the family says that "This [illness] is not a mental illness." It is only because the patient can't sleep (N1: p.12-13).

The main barrier is because they are ashamed if their family member suffers from mental illness. "If I am known by neighbors, 'whew, what will happen?'" Finally, the patient is caged in the room, or other ways ... what I know, it is the way they treat the sufferer, like that. Usually, from our assessment, we get

this information. Usually after assessment, most mentally ill people are from the rich people. Therefore, they use *Jamkesmas* - *Jamkesda*, poor letter, because they have been everywhere for many treatments (N12: p.13).

Stigma, um um, yes. The family and community members are scared of mental disorders. If someone gets sick, they consider that they have ancestors who suffered from mental illness; then, therefore they feel shy. Very often, during assessment, we ask the family: "Do you have someone else who suffers from illness like this?" "No, nobody else in my family is like this, only this one." Often we encounter that. Yes, they are ashamed ... Yes stigma ... they are still scared (N2: p.14).

Ashamed of disgrace

People with a mental illness bring shame on a family or discredit family members in Indonesian society. As a result, families, especially rich families, are reluctant to bring their relatives to the hospital and thus they do not receive the care that they need.

The first, because of feelings of shame ... Yes, because our society assumes that mental illness is a disgrace ... a humiliation because of sin, etc. Disgrace is a bad thing. Therefore, if they go to the mental hospital for treatment, everyone will know, right? The neighbors will know (N15: p.16).

Being hidden

According to one patient, his family is ashamed and hides his mental illness from relatives, who then are not aware of what is happening with him.

In my family, my uncles, aunts, etc., they don't know that I am sick. My father and my mother hide that. They hide the fact. Nobody should know because they are ashamed. But after awhile, since I was violent in front of my family members, cousins, they begin to know about me there. My aunt says: "Why didn't you mention that there is a problem? We can help you too." (P10: p.19).

Because families are ashamed, sometimes they hide a patient at a mental hospital or another place far from home to prevent their mentally ill relative from marrying. As one nurse indicates, there is a societal belief that if one sibling has a mental illness, other siblings will too.

“Don’t, no way,” they say. “You must see first before you marry her,” - like that. Sometimes if someone wants to marry, the family member [the patient] is brought to the hospital first. Sometimes, he is restrained [pasung], put away, isolated first ... put away. After marriage, [the other family] finds out about it. Finally, divorce. It happened for a girl who has a brother suffering from mental illness; [for they believe that] his sister will have mental illness too. Because after marriage, the family knows that the husband has a family member who suffers from mental illness. So, another additional [patient] will be in the family. It is still like that sir (N4: p.17-18).

Lack of family support

Family members play an important role in supporting a patient with a mental health illness, but they are often able to provide only minimal support because of their shame, fear, and anger. Due to this lack of support, patients often become homeless and their families do not try to find them. Those patients who remain at home are often restrained, and are at risk of their mental illness becoming worse.

Ummm [pause]. Actually, supports from the family are minimal. Therefore, the patients become homeless; they aren’t searched for by their family. In addition, they should be cared in the hospital but they are restrained [pasung] because there is no support from family (N6: p.8).

One patient believes that the only support he receives from his family is support to be ‘crazy’ but not for recovery.

From family? No, zero, not at all. Since I have been here, I haven’t been visited yet. “Since I am here, I haven’t been visited, right?” [he asks a patient] ... yes, not yet (P14: p.6).

However, not all patients are without some support. One patient acknowledges that his family has assisted in making a plan to manage volatile situations and to remind him to take his medicines at home. Because his father is a medical doctor, it is reasonable to expect that they are not ashamed and know something vital can and is being done for their loved one.

Family support, yes, it is clear. Now that I am controlled, I am stable. Since that time, my family has begun to open to me. My uncle, Mr. I; he starts talking to me. He pays attention to me too so that I start praying tahajjud [midnight praying]. I start praying at the mosque. I am close to him. My uncle, uncle N; he is my father's brother. He pays attention to me, my interactions; "you are good, he says."...Yes, it is clear. I must take my medicines continuously. My father knows best, right. He is the master. He is similar to you too (P10: p. 10-11).

Another patient who enjoys support from her family may have it because she was newly admitted.

First, they used their working time; yesterday, they were here. My family members visited, their children were brought. It means that there is attention, Alhamdulillah (thanks God). Food at home is ready. My sister and cousins do that. Basically, she wants me to use the hijab [veil]. My sister-in-law, my family, visits me. I give them money 15 thousand rupiah. A lot of support from them. Furthermore, they say: "you just stay here because you have insurance; insurance for three months" (P13: p.6-7).

Lack of social support

As the above indicates, the social support needed to promote and support independence and quality of life for the mentally ill is lacking; many are still discredited, insulted and shunned, leading to social isolation.

Yes, that happens in Indonesia. Some people are good, some are bad. [Sufferers] are expelled, discredited, put away. So basically, Indonesian people behave badly toward people with a mental illness. It isn't really good ... Mentally ill people are not involved in daily social activities, because they have a disorder. How can they be involved? They are mentally ill sufferers. They are unable to care for themselves. How can they be involved? (P11: p.16-17)

Feel better to be in hospital

Some participants believe they are better off in hospital because of a lack of societal acceptance. They have the feeling of being at home without the abuse often received there.

It is better here sir. Yes, if I am at home, many voices around. When I relapse again, how to handle it? For that reason, I avoid being at home. I bring myself here. If I go to Java (Island), I will not be accepted anymore. If I want to work

at the Bidakara hotel I will not be accepted anymore, because of a blacklist. In my community, I am not accepted sir. I am not valued. I will be discredited forever. I am isolated. Therefore, it is better to be here. Here, everyone is my brother, my community. For that reason, I come here [and find it much like coming home] (P1: p.8-9)

Their social rejection leads to isolation and lack of community support, especially if patients have exhibited violent behaviour in the past.

Some of the patients are afraid to go home because their societies have isolated them. There is a statement in the community that “if someone has come back from a mental hospital, he is not allowed to go back to the community [or] if he does go back to his community, they will go.” So the patient thinks, Why does this happen when I want to go home? Because in the past, I was violent; threw glasses, hit my family, etc. so people in the society don’t accept me anymore. How could I go home, nurse?(N13: p.7).

Community members keep away from them. [Sufferers] aren’t included in activities. Yes, it is clear; [community members] keep away. [Sufferers] are insulted, discredited. If you see OVJ [a TV show], crazy people are insulted there (P10: p.15).

Patients understand that they are labeled or blacklisted, and fear for their future.

Yes, it is a label. I can be blacklisted in the future. It makes me worried ... AB has been in a Nusakambangan [a jail in Indonesia], UP has been blacklisted. It will be difficult for me ... I will be hated (P14: p.12).

Some patients are rejected if they want to work. According to one nurse, people are afraid to hire the patient because of his history of violent behaviour. Another nurse indicates the patient is not asked back to work again since community members are afraid he will still be violent.

Because of this stigma, it is true. Some patients still have the intention to work, but ... for example, there is a patient here, and he works usually as a coolie. He says to me, “I am always a coolie. [But] since I was violent, nurse, when I go home, nobody wants to ask me to work anymore. I am stressed again.” So what to do, right? We are here; we improve their self-confidence so that they can go back to the society again. But their community members are worried, scared. They are scared if the patients should become violent again, disturb the community again. Social stigma, there is a worry in the community that if the patients come back to society, their condition will be similar to their

condition in the past (N11: p.8).

4.5. CATEGORY 5: STIGMATIZATION

The living conditions of people with mental illness not only depend on the severity of the illness, but also on the level of their stigmatization by their family, community, and healthcare professionals. In this part, the stigmatization process will be explained based on Link and Phelan's (2001) components of stigma: labeling, stereotyping, separation, and status loss and discrimination.

4.5.1. Labeling

Crazy person

According to participants, people in society still label the mentally ill person as 'crazy' or 'ex-crazy.' A person is considered crazy just for going to see a psychiatrist at the RSMM, because of the label of the hospital as a "mental" hospital.

[Patients] are looked down upon if they go to psychiatrists, they are not [considered] true people. They are assumed to be abnormal, their brains are unhealthy. [People believe that] if someone goes to a mental hospital, she won't recover when she comes back home, instead, when she comes back from hospital, she will be worse. The people's opinion in Indonesia is like that. Yes, if people go to the hospital, they won't recover ... but will be more 'crazy' because they come from a mental hospital. In America, if they go to a psychiatrist, they will be fresh and it is a sign that their problems have been solved. Here, it isn't similar to that. If I am from [the RSMM], my label is bad. If I go to the mental hospital, I am labeled that I am a mentally ill person ... For me; I am here because I want to recover. However, other people see or consider that I am sick ... [But] I don't care. The most important [thing is that] my problems are solved. If they have medical treatment, they are assumed to be mental illness sufferers. [Although] they have treatment [to help you recover, instead you are] labeled as being sick, instead of in recovery, it is true, right? (P7: p.7-8).

When patients are discharged back into the community, they can never escape the label of mental illness and are often shunned.

Automatically, if the patient goes home, sorry, they are discredited, insulted, “you are crazy.” Because of the lack of knowledge in our families and society, patients are insulted. They don’t feel comfortable, right? ... When a patient is at home, some community members still say “wow, he is a crazy person.” Actually, for the patient so ... so, there is no recognition in the community (N10: p.13).

However, patients often reject the label of being mentally ill.

Yes, it is ... it is a big problem because I don’t have a sin. I didn’t make a mistake ... [In the hospital] I am considered a mentally ill person. I am considered a person who suffers from mental illness, but before I was caught ... I was at a midwife’s with an abdominal pain. I was taken from home, like that. I was just having a nap ... I was just taken and put in the car. It was like that sir ... I was in shock. I screamed ... What was happening, what was wrong?” What if my family knew that I was brought to be with [strangers]. I didn’t understand (P6: p.3).

Families ashamed of the label of ‘mental illness’

Families are afraid of the label of mental illness and are ashamed when others find out if one of their members suffers from this condition.

There is a feeling of being ashamed; mostly, of feeling ashamed. For example, if they come to the polyclinic in the mental hospital, they say: “what will the other people say?” If I come [to the hospital] and I am given medicines, what will the other people say?” – like that. When I ask for help from the community, whew, what will the people think? If community members know that my son has a mental illness, whew ... I will be ashamed (N13: p.10).

Labelling of nurses

Being labeled a “crazy nurse” because they work in a psychiatric hospital often leaves nurses feeling humiliated and insulted. They say that many people assume the hospital is an asylum.

Very often, I am asked ... Before, its name wasn’t RSMM but Bogor mental hospital. I am often being told or called by other people: “wuihhhhh [insult] ... working in that hospital? ... The mental hospital in Bogor?” Those people say: “working with the crazy people?” However, I say that I am not a crazy nurse; I am a mental health nurse but in their perception, I am a crazy nurse ... Whew ... a crazy nurse (N13: p.15).

One nurse participant who cares for *gelo* [crazy people] states that other nurses label him as “crazy” as his patients.

Sometimes, I experience [stigma]. Sometimes, if I talk illogically, people say “ohhhhhh [its] because you are psychiatric nurse.” I always experience and hear in our community: “Uhhhhh ... yeahh, since he works to care for the *gelo* [crazy] people.” They say “whew psychiatric nurse.” Sometimes this stigma sticks to the nurses from people in our society. Yes ... also, we are labelled by our friends [nurses]. They are either joking or serious, I do not know. In addition, my friends say: “ihhhhh ... whew, psychiatric nurse.” Yes, similar, as crazy as his patients (N6: p.15).

As one nurse complained, people still insult psychiatric nurses.

They insult me. At a family meeting, I explain that having a mental illness is not a contaminating illness. I was pissed. My family is terrible, right? Even if they are my family, they still don’t accept it. Yes, I have, it is right. When they know that I work at the RSMM, my husband’s family, my sisters-in-law say:” Whew, do you work at the mental hospital. Aren’t you afraid when your wife works? You pick up your wife, aren’t you afraid?” Hmmmmm [angry] ... how do I feel? I am angry, right? (N4: p.18).

4.5.2. Stereotyping

Powerless person

Patients with a mental illness are believed to be powerless because of a perceived lack of control, and others question the rights and abilities of these patients to be involved in daily activities. As one nurse participant points out,

Umm ... The form of this stigma, they have suffered from mental illness. They are helpless and powerless. "They suffer from mental illness right? Why are they involved in the family and making decisions?" It can be also ... because their conditions are labile, angry, interfering ... (N7: p.5).

There is a strong stereotype that the mentally ill are dirty, disgusting, or sickening, perhaps mainly because many of them are homeless.

Like this, people outside assume that crazy people are very dirty. Terrible ... [unclear], disgusting, sickening, and cloying. So [sufferers] are treated inhumanely ... Even if they are an actress, a member of the DPR [senate] or a president, when they are “crazy,” that will be their condition (P3: p.6-7).

In addition, patients are assumed to be social garbage, which in Indonesian terms means that they are considered useless and of no benefit to other people in society.

They [patients] are discredited; abused sir and they are assumed to be garbage by society. (P15: p.15).

Person with difficult life

Many people believe that the mentally ill will have a much lower life expectancy, due to their difficult lives and their lack of hope for a future.

This is related to stigma, a social stigma. Yes, they see that patients' life expectancy is not good; many, most of them ... Generally, if someone suffers from mental illness, there is a stigma or label that ... Um um, there is a label that they will have a difficult life, that they will have difficulty finding a job, someone to marry, living normally in society. So, uh ... many bad perceptions (N15: p.17).

Untreatable illness

Many people also have the stereotype that mental illness is an incurable and unalterable illness. In fact, it is clearly shown that the majority of people with a mental health problem could be helped to live independently. However, there is an assumption that they are not able to function normally even after receiving medication, or they must take medication forever.

Patients are considered scary and dangerous, and are looked down upon ... Yes, they are avoided ... Then, they are not supported. Some believe that the patients cannot recover. They must take medication for their lifetime (N2: p.17).

Indonesian people assume, they are abnormal and cannot be managed. They have been considered as a tangled thread ... I will take medicine until I die. It is considered that they will never recover, that they will relapse (P5: p.11).

Social disgrace

People with a mental illness are considered a social disgrace, because they have an

illness brought on by being cursed or sinful.

Generally, Indonesian society ... still considers that a person with mental illness is a disgrace for them. Disgrace and sin are similar in people's view. Yes, it is almost the same. Disgrace, "Oh, he suffers from mental illness, like this, like that ... Disgrace and stigma are the same" (N12: p.15).

The psychiatric hospital as a dangerous place

Many nurse participants spoke of the stereotype that the psychiatric hospital is a dangerous place to work – that it is a risky place because the mentally ill are violent and dangerous. Not only community members but also general nurses assume that the mental health nurse is threatened both mentally and physically.

For example, [the psychiatric hospital is considered a] dangerous, or risky place to work. Friends have told me, yes they have sir. My friends, when I was at the University of Indonesia, said; "whew ... you work in RSMM Bogor?" Are you really working in a mental hospital? Taking care of mentally ill people? Why do you like working there?" My friends work at the RSCM [general hospital at Jakarta]; "ihhhhhhh [afraid] taking care of mentally ill patients." They know that I work with mentally ill people. They have practiced here before and saw how to bathe patients. Also, patients defecate and urinate everywhere (N2: p.18).

4.5.3. Separation

Loss of families

Since many patients are abandoned by their families when they enter hospital, they suffer the loss of their family over their mental illness. Some male patient participants have separated from their wives and children because of their illness.

I have been separated from my wife [cries]. My wife is pretty and I am divorced. I am sad. I just pray to God. Where I ask when I am sad or happy. This life is about two choices. There is a heaven and a hell. There is a day and a night. I am not with my wife. I am divorced. My wife has gone and she has built a home again. She sold my car. She said that the money was for our children. I do not know. She has been bored with me, since 2000. I have been with this illness since 2000 (P2: p.1-2).

Friends, relatives and community members don't want to interact with patients, and thus they feel rejected and isolated. According to one nurse, social rejection can trigger relapse in patients.

At home, besides places to work, they need the conditions and situations for support for recovery because many of them relapse again. They relapse because of stigma. For example, their friends don't want to interact with them again. The patients find it difficult to find a job. This situation will trigger the patients to be stressed again. "When I go home from here, I am good; then, when I'm home, and I look for a job, it will be difficult for me." In addition, I am ashamed to socialize with my neighbors." (N11: p.11).

In my opinion [ordinary people – even their friends] only rarely support them, sir. Instead, they are avoided. I mean their friends don't want to interact with them because they are different sir. Mentally ill people, sometimes they talk to themselves. It is like that right? Um um, they are not supported. But, they are avoided, right? (N14: p.7).

[Patients] are suffering, sad. They are marginalized. They are sad because of stigma. People who suffer from mental illness are considered useless to society; people assume that. People still are afraid and the community still isolates [these people]. In my community some people suffer from mental illness. As a mental health nurse, I try to make sure to tell my neighbors that patients with mental illness still can be productive. They still can socialize. They still can be included social activities (N7: p.4).

Self-avoidance

People suffering from a mental illness who are shunned by other people in society often begin to consider themselves socially inept or personally incapable. Thus, in turn, they avoid social interaction because of the fear of being rejected, humiliated, or ridiculed by others. One participant avoids contact with others because she believes herself to be a low and useless person.

I don't have friends. I am lazy to make friends. As if my friends want to avoid me again. Yes, I feel that. I feel it more and more severely. I feel that I have no friends. But there is a friend who is still good to me. TG, he is good and comes to my home. I isolate myself and don't want to go to the school. He comes to my home, he is my classmate. He shakes my hand and smiles at me. (P10: p.24).

I eschew [contacts] sir. I avoid [them] sir. Yes, I have low self-confidence because they assume ... when girls, they are beautiful, rich, and smart so that I am feeling low. Contemptible ... Low ... Despicable ... In addition, they think that we are garbage, 'crazy'. All people do that. People of Indonesia think like that sir (P3: p.3).

Another patient only socializes with the hospital security guard, and he is hurt because people see him as a low and disgusting person.

For me, I do not interact with [people] totally. I just socialize with the security guard. I like to sit in the security post. They like to mention it... and it hurts me. Clearly, it hurts me. Therefore, because of that I wake up sir. I crochet, crochet, and crochet continuously. Low down, disgusting, [people] look down [on me] (P3: p.6).

4.5.4. Status Loss and Discrimination

Participants say that the social stigma attached to mental illness and the discrimination they experience have concrete effects. Many people's problems related to mental illness are made worse by the discrimination they experience in their daily life from society, families, and friends. People with a mental illness understand that they can be treated unfairly in their everyday lives.

[Sufferers] are isolated and not accepted, right? Yes, they are ... It is better to be silent than to argue. It is the best way to be safe. If I argue, I am assumed to be "crazy"... I have a history [in the RSMM] ... If normal people do something wrong, it is assumed to be ok, fair, usual. If crazy people do something different, even it is not wrong yet, they are assumed "crazy." Yes. "Whew, you are crazy; you must be in a mental hospital." If we are angry, just accept it [istighfar]. It can be solved. (P5: p. 3-4).

Being discriminated against

The fact that the mentally ill are considered dangerous and harmful leads to them being ignored or abandoned. But as one patient points out:

Criminal people are worse; people in jails are worse than people in the mental hospitals. In the jails it is scarier. Now, all are in the jails ... Yes, they are afraid of people with mental illness. (P7: p.14-15).

Patients are homeless and wandering

In Indonesian society, many people with mental illness are homeless or wandering, because they are unable to maintain safe and adequate housing. Any disturbance from them can see them expelled from any kind of shelter they can find, forcing them to find food in trash bins.

On the street, they eat haphazardly and everything. They pick garbage, like that right? So they have physical illness too. Physical mistreatment, for example, they are expelled, evicted. They are expelled from their community because they are thought to be disturbing others. Like that, right? So, they become homeless, like that ... Discredited (N6: p.7).

Patients feel a lack of respect from the wider society. The assumption that mental illness is untreatable makes them feel as if they are a burden to society, and they see little action by the government to change this attitude.

On average [community members] insult, discredit [us]. In addition, the government doesn't manage this problem. Almost 100% of the mentally ill are on the streets. At almost every corner, they are there. Treatments from society are mostly inhumane. (P14: p.14).

At least one patient talked about the overt discrimination he had encountered.

Then, I had an experience in Universitas Terbuka sir. There, I didn't know why, I was treated badly. I bought a book; I was put last in line. I mean, people bought books, people were queued, and I was put last in line. Other people were first. I was considered as nobody. I was considered nobody there, I wasn't important, it is still like that. The [sufferer] isn't important. "Who is he? Why he is there?" (P10: p.7).

Some of the patients see families discriminating between a mental illness and a physical illness.

There is discrimination. [Family members] don't make it equal with physically ill people, right? Yes, they discriminate (P5: p.2).

The labelling of people with a mental illness in Indonesian society has grave implications for their careers.

In the community, people see me; “wheh a professor’s patient.” People say “wuhh wuhh” [lowl], “the patient of doctor R, wuhhh.” Yes, they do look down on me. If I visit my professor, my label is not for recovery ... instead, they label me as the professor’s patient; it means that I am a mentally ill person. It is like that outside. I don’t know, is it just my feeling? Or do they consider me like that? But it is true about that (P7: p.12).

One patient mentions that he is worried about his career in politics because he is blacklisted as a mentally ill person.

This blacklist, I worry about in the future, my career in politics ... in the future. [The label] discredits me. Yes, it is discrimination. Yes, I am afraid of that. Automatically, my career in politics will be over (P14: p.12-13).

Another patient contends that the government will not allow him to work again because he is a mentally ill person.

Often, most people in our society don’t want to accept the sufferer ... “An ex-crazy person,” they say. But the US president was a “crazy person” too ... For me, although I am not accepted by society, I do not care. I want to be a MPR [senator] later (P2: p.8).

In addition, in television and the newspapers, patients are insulted or parodied and therefore discredited.

If you see OVJ [a TV show], crazy people are insulted there. Yes, it is a parody (P10: p.24).

Indeed, even those with health education can be afraid of those with mental disorders. People with a mental illness are still stigmatized even by those who are educated, including nurses who work in general hospitals.

Yes ... all over Indonesia [people are] still stigmatized. Not only for [the general population in] Indonesia who don’t understand, but also people who have health education sometimes; [they] still stigmatize people with mental illness. Many of us do, we don’t deny it, our friends [other nurses] who work in non-mental health facilities. For sure, approaching mentally ill people, they are afraid (N3: p.15).

For example, a nurse participant recognizes that even he or she still discriminates against people she knows.

I have had a house assistant who has been violent. She works at my parents-in-law; I was worried to leave her at home alone. I asked: “do you hear voices? She said “yes.” I was scared too. Fortunately, she asked to resign (N2: p.12).

But nurses working with the mentally ill also face discrimination themselves.

Whew ... I often met with friends from outside the area of mental health nursing. When I was asked, “what is your name? What institution are you from?” I said, “From the mental hospital at Bogor.” That time, they all laughed. Everybody laughed. They laughed at me. I said “if I don’t come, nobody laughs right?” But I have ability. At the dinner time, I explained about my patients that they are, like this, like that. However, their reaction at first was insulting. I am sure that my nurse colleagues [will have the same experience]. At a palliative care training meeting in the hospital at Dharmais [they said], “whew ... from the mental hospital, what do you want to learn?” [laughs]. At a training of trainers meeting in Surabaya ... “Ihhhhh [insult]... From the mental hospital ... What do you think?” [laughs] Moreover, in an infection control meeting, they are surprised that a mental health nurse comes. “Mrs. S. is from where? Are you from the mental hospital? What will be studied related to an infection problem?” (N7: p.14).

Mental health nursing is considered a less prestigious part of the profession

Not only the general population, but also other nurses still don’t understand the kind of work that psychiatric nurses do.

I feel that mental health nurses are underestimated by other nurses. Related to prestige, there is an assumption that, “if you work in a mental hospital, you have much free time, right?” Then, “why do you want to work in a mental hospital, [there is] nothing to do there.” Actually, I want mental health nursing [to be considered] more modern. I saw on TV and in Western films that mental health nursing is developing well. We want our societies to have a positive assumption similar to western people. (N11: p.15).

Some nurses believe that changing standards in mental health nursing will help eventually eliminate the discrimination against mental health nursing.

Not only in public, but also in our nursing profession, mental health nurses are considered a sub-standard part of the profession. However, now with

improvement, with our current standards, we are now equal ... Now our condition is much better. Now we can announce to our profession that “we are mental health nurses.” Yes, but in the past, we could not... [they would say]“Whew, mental health nurse, do you work in mental hospital? You could be contaminated.” However, now, we have colleagues who could improve our mental health nursing area. There are masters (of nursing) who will improve our mental health nursing profession (N1: p.17).

4.6. SUMMARY AND INTEGRATION OF STUDY RESULTS

Mental illness in Indonesia has multiple dimensions for patients, families, community members, hospital staff, and government. Visiting “smart” people, such as Islamic religious leaders, chaplains, dukuns or shamans, or those dispensing traditional Chinese medicine, is usually the first choice of family and other community members dealing with a mentally ill person. They go to alternative healers partly because they deny that their family member suffers from mental illness. They also believe that mental illness is caused by the possession of demons, Satans, spirits, or devils. Treatment at the alternative healers, however, can often be brutal; some patients have encountered physical abuse in the forms of whipping, being plunged into water, enduring hard massage, or being forced to eat unwanted foods. Some are left to fend for themselves in the jungle, leaving many patients to feel that they are treated like animals.

But patients also fear more modern treatments in psychiatric hospitals, especially if they have been forced into treatment there. They face both physical and psychological barriers to treatment, including distance to the hospital, feelings of shame, and lack of knowledge or information about mental illness. Fears that hospital treatment is also too expensive, that those, particularly from rural areas, will not be admitted, or that family members are afraid of the potential for drug dependence are other barriers to obtaining the help sufferers need.

Nevertheless, basic facilities and services are provided by the RSMM, including food, some clothing, and a rehabilitation center for socialization among patients and between patients and nurses. At the RSMM, medications are the first line of treatment but ECT can be used if the patient's condition does not improve. The RSMM hospital has an inter-professional model of patient care – a collaborative patient-centered practice to guide the delivery of care for mentally ill patients. It consists of medical doctors, nurses, nutritionists, laboratory staff, x-ray technicians, and physiotherapists who work collaboratively to deliver quality care within the hospital setting. Nursing care is guided by standard operating procedures (SOPs), which provide a method called MPKP (Professional Nursing Practice Model). Rumah Sakit Marzoeeki Mahdi (RSMM) attempts to employ enough qualified nurses to make an effective workforce. In addition, staff nurses are routinely required to undertake administrative tasks as part of their professional skills. Psychiatric nursing care at the hospital is based on nursing care plans (NCPs).

Outside of the hospital, many patients can access a range of community services. There are some private foundations or institutions for those who are better off, or Puskesmas or public health centers, and Posyandu. Community mental health nursing is available to support or treat people with mental illness. Some of the community-based outpatient facilities have instituted the ACT program, a model of mental health services delivery that offers patients different services to help them live independently in their community. Nurses also conduct home visits as a community program, where they address issues related to basic mental health care, good parenting practices, safe home environments, and offer access to mental health services, counseling programs, and basic health care planning and its implementation. One issue related to home visiting is dropping, carried out by the nurses if

family and relatives refuse to accept the patients voluntarily or if they will not come to the hospital to take the patient home.

Despite the importance of support for patients, however, many families have little. They are burdened by the care of patients if they are at home, and they are not given adequate information regarding the problem, treatment, or available resources. Some patients indicate that they have been abandoned and deserted by their families during hospitalization. Social care or support provided by community members is also very limited, leading to the homelessness and abandonment of many patients. Community members tend to shun the mentally ill and do not include them in community activities. Nonetheless, the government has instituted health insurance for poor mentally ill patients to improve access to and the quality of health care services. The Health Insurance Scheme for the Poor (Jamkesmas), is managed by the Ministry of Health for Indonesia, while Jamkesda is health insurance provided by the local government district under a provincial governor and is run by the provincial health department.

As the results of this study have shown, patients, in seeking treatment, have met with violence and fear, leading to their construction as cursed people. Violence takes several forms: patients can attempt to hurt themselves (suicidal ideation) or they can engage in violent behaviour such as fighting or throwing things at relatives and community members. Much of this violence is in response to the treatment they have received, especially the forms of restraint (pasung) and seclusion (seklusi) where patients may be caged, tied, chained, handcuffed, or put in wooden blocks (balok). According to some patient participants, however, they have experienced physical abuse even in the RSMM where they can also be

restrained or put into seclusion. The data analysis shows that patients were victims also of psychological abuse perpetrated by nurses and other hospital staff.

According to nurse participants, there is a great lack of knowledge about mental health and mental illness that has led to much fear and shame among family and community members, as well as the patients themselves. Some people believe that mental illness is hereditary, is a contagious disease, or brings social disgrace. Families and their mentally ill relatives have been expelled by their community, or have simply disappeared. Both physical and psychological abuse and humiliation have led to patients being avoided, rejected, and neglected, and thus isolated, hidden, or abandoned to the streets. Television shows and other media have also parodied the mentally ill, adding to the negative impact of this discrediting.

People with mental illness continue to be labelled by those in Indonesian society as crazy or ex-crazy, violent or dangerous, powerless, useless, wrong or irresponsible, unfortunate or unlucky, or having a low status. The stereotype persists that mental illness is an incurable and unalterable illness, and that the mentally ill are not able to function normally even after receiving treatment. The patients experience damaging separation – they are abandoned by their families or isolated from involvement in community activities. All of these factors lead to severe forms of discrimination and loss of status, since these patients are considered less equal to others in their society. Both the severity of their illness and the level of stigmatization they receive affects the living conditions of people with a mental illness. Many are prevented from earning an income or from taking part in other forms of community life and end up homeless.

Mental health nurses, too, have felt the influence of these attitudes toward the mentally ill. As the study data revealed, some patients believed that some nurses and other health

professionals held negative feelings towards them, and some nurses admitted that their colleagues mirrored general society in their beliefs that mental illness was contagious. Many mental health nurses have felt insulted by other nurses and had their work with these patients demeaned and devalued. They have had to fight the assumption that working in a psychiatric hospital is risky. Although there are signs of change, mental health nursing has been considered a lower part of the profession.

The goal of integration is to link categories and compare them to one another according to their properties. In this research, five descriptive categories were produced, with the fourth category (constructing cursed citizen) identified as the primary conceptual element (core category) where all other categories converged. Although each category could be explored in isolation from the others (mutual exclusion), all are interconnected.

The first link is a connection between violence, fear, treatment, and stigmatization. People sometimes think mental illness and violence always go together and they are afraid of the mentally ill because of their violent behaviour. Violence is also linked to treatment, especially the inhumane treatment of traditional healers which can either be physical or psychological. Fear, an emotion induced by a threat, is experienced by patients, families, society, and nurses. It arises from the perception of danger from patients' violence, which, when patients are avoided or isolated, can lead to further violence. Fear of patients is the result of specific situations (angry or violent behaviour) in a specific setting (home, society or hospital), where patients are defined as potential risks. As such, people stigmatize the patient as dangerous or unsafe. In addition, the fear experienced by other people contributes to the construction of cursed citizens. The study results reveal that some patients and their families are afraid to access modern health facilities (hospitals) because they fear that the

hospital will reject them. They also fear that patients on psychiatric drugs will become drug dependents.

The product of all three categories (violence, fear, and treatment) enables the process of constructing cursed citizens. The category of stigmatization – labeling, stereotyping, separation and discrimination – is built on the myths and misconceptions about mental illness that are significantly prevalent among families and communities. The belief that mental illness is provoked by spirit or demon possession leads to fear and the violence of treatment measures, again constructing the cursed citizen.

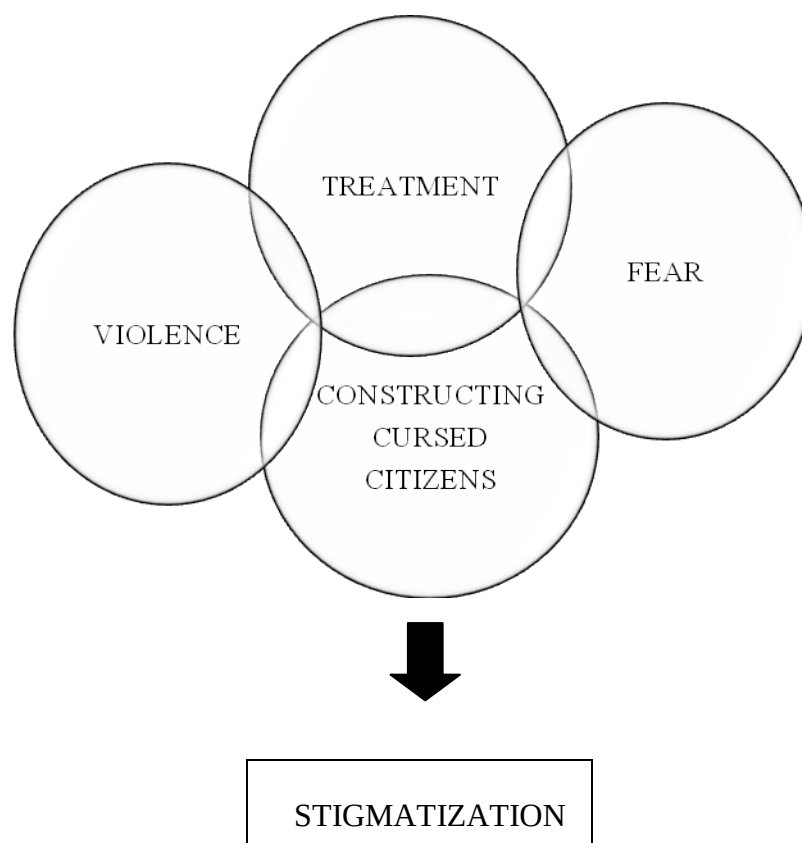
The results of the study indicate that the stigmatization of mental illness is a social process related to personal experience characterized by exclusion, isolation, fear, rejection, blame, violence, or devaluation. Stigma outcomes can be divided into four distinct types: self-stigma, public/social stigma, professional stigma, and institutional or governmental stigma. Self-stigma is the internalizing by the patients of their perceptions of stigmatization. It negatively affects any positive feelings they might have about themselves and leads to poorer health status and treatment outcomes. By internalizing these negative beliefs, patients and their families experience feelings of shame, hopelessness, anger, or despair that keep them from seeking social support or treatment for mental illness. Social or public stigma is characterized by the negative feelings, attitudes, and behaviours resulting from the widespread endorsement and implementation of labels, stereotypes, prejudice, status loss and discrimination of people with mental illness. Public stigma has an impact on patients' negative feelings, making them feel guilty and inadequate.

Professional stigma held by nurse professionals develops very much in the same way as social stigma in the general public. For example, staff nurses maintain social distance

from patients because they believe that mental illness is a contagious illness. Nurses themselves are also the recipients of stigma because their work and their workplace are seen as dangerous. Institutional stigma refers to an organization's policies or culture of negative attitudes and beliefs. For example, stigma is often reflected in the use of mental health terms, such as mental hospital, psychiatric patients, or schizophrenics. Institutional stigma occurs when assumptions about persons with mental illness are translated into actions or decisions that discriminate against people with mental illness. Professional and institutional stigmas are often interchangeable.

The link between mental illness and stigma is promoted and exacerbated by the media. Mass media have the power to impact public perception and the degree to which people are exposed to media representations makes the mass media one of the most significant influences in developing negative attitudes towards mental illness. Television, radio, newspapers, and films often portray sufferers as bad, wrong, criminal, evil, or unable to live a normal life.

Figure 4.1: Categories



CHAPTER 5

DISCUSSION AND CONCLUSION

The purpose of this chapter is to discuss the major findings related to this research, which will be compared and contrasted to existing theories and current literature.

The Stigmatization Process

Stigma is a worldwide concern that adversely impacts the available opportunities and quality of life of people who suffer from mental illness. It is a severe burden for sufferers both in their private and public lives, and it also affects their relatives or those who make up their close social networks, as well as those involved in the mental healthcare system (Gaebel et al., 2011). Goffman (1963), as well as Corrigan and Penn (1999), have shown that people who have been diagnosed with a mental illness face many challenges due to the level of their stigmatization by other people (family, community, and healthcare professionals). Prejudicial and discriminatory behaviors stemming from stigmatizing beliefs and attitudes make it difficult to find employment (Cechnicki, Angermeyer and Bielańska, 2011; Sharac, McCrone, Clement and Thornicroft, 2010) or proper housing (Livingston and Boyd, 2010; Wahl, 1999). In addition, stigma diminishes hope, self-esteem, self-efficacy, and empowerment for people with mental illness (Livingston and Boyd, 2010). Some studies find that stigmatizing people with mental illness has happened on all continents: Latin America (de Toledo Piza, Peluso, and Blay, 2004), Asia (Lauber and Rössler, 2007), Africa (Adewuya and Makanjuola, 2005), the United States (Anglin, Link, and Phelan, 2006; Pescosolido et al., 2010), Europe (Mehta et al, 2009), and Australia (Jorm and Wright, 2005).

Link and Phelan (2001) concluded that “stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation”

(p.377). Individual differences are first distinguished and labelled. Cultural beliefs then link labelled individuals to undesirable characteristics and negative stereotypes. In the third element, labelled individuals are placed in distinct categories so as to separate 'us' from 'them'. Finally, labelled individuals experience loss of status and discrimination, which leads to social exclusion. These elements encompass the understanding of stigma as defined by Goffman (1963), in that characteristics of the out-group are deemed socially undesirable and its members acquire a spoilt identity, leading to devaluation and discrimination. Link and Phelan's (2001) view of stigma also built on the concept provided by Goffman (1963) by adding that stigmatization was contingent upon access to social, political, and economic power, the loss or denial of which allowed the identification of differences, the construction of stereotypes, the separation of labelled individuals, and discrimination.

Labeling

In Indonesia, the results of this study show that participants were labelled "crazy" or "ex-crazy" persons, and if it was known that they had come to a mental hospital, they were labelled as a "mentally ill patient." Labelling affects not only those with a mental illness but also those who come in contact with them, including mental health professionals who treat them. This is especially true for nurses, who were sometimes called "crazy nurses." Studies found that labels are an important part of stigmatization, contributing to all four components of the stigmatization process (Link and Phelan, 2001; Phelan and Basow, 2007). Mental illness diagnoses often come with the additional burden of a negative label that can prevent people from seeking care (Clark, 2008; Lai, Hong and Chee, 2000). Other authors agree that examples of labels or terms that are used to identify or describe a person with mental illness include the "mentally ill," "abnormal," "insane," and "crazy" (Stuart, 2006; Wahl, 1992). The

use of derogatory language concerning such individuals is ubiquitous; for example, "retard," and "psycho" are common slurs across cultures that both children and adults often use casually (Hinshaw and Cicchetti, 2000).

Stereotyping

Stereotypes are knowledge structures that are acquired by people of a particular social group about people in other groups (Corrigan, Larson and Rüsch, 2009). These stereotypes can form and reflect negative beliefs about a group. Goffman's (1963) work on stigma included a discussion of the link between attributes and stereotypes. According to Crocker, Major and Steele (1998), the stereotypes that address the most severely stigmatized identities may become ubiquitous and accepted as facts, resulting in widespread devaluation that affects the lives of stigmatized people in ways that are often difficult to determine.

The participants in this study indicated the ways people with mental illness encounter stereotyping in multiple settings, whether in a personal interaction, or within broader contexts such as the media, community, and the healthcare system. Some cultures fear that people with a mental illness will cause havoc in the community and are considered a social disgrace, especially in those, like Indonesia, who believe mental illness is a cursed and sinful illness. People's understanding of mental health treatment also rests on the belief that mental illness is incurable and unalterable (Corrigan et al., 2002; Corrigan and Watson, 2005). It is assumed that the mentally ill are not able to function normally even after receiving medication or that they must take medication forever. Others usually do not sympathize with a mentally ill person; they believe that the person lacks the will power to pull him or herself up and is just not making an effort (WHO, 2001). People with a mental illness are also often depicted as inadequate and unlikeable (Stout, Villegas and Jennings, 2004), and as this study

has found, sufferers can be considered social garbage or useless people. Many people believe that someone with a mental illness may only recover with the urging of an authoritarian person ensuring the recovery, maintenance, and treatment of the individual (Kobau et al., 2010); they need life decisions made by others because they are not responsible and need to be taken care of like children (Corrigan and Watson, 2002).

Despite research that has documented that only a few of the mentally ill are actually violent (Corrigan, Larson and Rusch, 2009; Link et al., 1999), the stereotype persists that people with mental illness are dangerous, meaning that they are unpredictable and threatening (Ayazi et al., 2014; Jorm and Griffiths, 2008). According to Angermeyer and Matschinger (2003), endorsing the stereotype of dangerousness has a strong negative effect on the way people react emotionally to someone with a mental illness, especially schizophrenia. Nurses who work with mentally ill patients can also be negatively stereotyped in that they are seen to be contaminated by patients' mental illnesses or that their work is risky. In mental healthcare settings, professional staff may also hold negative attitudes and beliefs about people with mental illness, attitudes that have implications for patient treatment (Hansson, Jormfeldt, Svedberg and Svensson, 2013).

Separation

Separation comes from a strong focus on difference. Linking the mentally ill with stereotypes about them provides the basis for social distance and exclusion, and poor community attitudes towards sufferers make their reintegration into society a difficult task (Audu, et al., 2013). Michaels et al., (2012) indicate that societal misunderstandings of mental disorders lead to the social exclusion of people with mental illness. In the Sudan in Africa, one study found education made a difference – people with low education levels and

who thought the mentally ill were dangerous were more socially distant while those who endorsed community-oriented attitudes about healthcare were more likely to show a decreased social distance (Ayazi, et al., 2014).

Status loss and discrimination

The results of this study indicate that there is a social distance or separation between people with mental illness and other people in their community. Many of the participants were abandoned and ignored by families and community members who did not want to socialize with those displaying abnormal behaviors. This social rejection led some to be more ashamed or angry about their mental illness, tending to focus on their weaknesses or mistakes and blaming themselves for any difficulties or failures. Patients then withdrew from their daily social life. Corrigan and Rao (2012) define social avoidance from the patient's perspective as a protective factor where individuals with mental illness circumvent any social situation where others may discover their diagnosis. In one study, when patients pursuing higher education were asked about their willingness to disclose their illness, they opted to protect their vulnerable identity (Martin, 2010).

As this study has also shown, Indonesian people with mental illness have experienced discrimination in their daily life, in the hospital, and in community settings. Many relatives and community members feel threatened or uncomfortable when confronted by sufferers. The effects of discrimination from stigma among patients with mental illness are well known (Amalia, 2010; Hinshaw and Cicchetti, 2007; Link et al., 2004; Rasmun, 2001). People with mental illness are subjected to systematic disadvantages in most areas of their lives such as at home, at work, in personal life, in social activities, in healthcare, and in the media (Corrigan, 2005; Link et al., 2001; Wahl, 1995), making marriage, childcare, work, and a

normal social life much more difficult (Peterson, Pere, Sheehan and Surgenor, 2006).

A cross-cultural study of employers' attitudes demonstrated that people with mental illnesses are among the last to be considered for employment (Brohan et al., 2012; Corrigan et al., 2010), and unemployment rates between 80 and 90% are not uncommon among severely mentally ill people (Stuart, 2004). Even when they do find work, their wages can be significantly lower than those of people without a mental illness performing the same jobs (Baldwin and Marcus, 2006).

Negative views about the mentally ill are also widely expressed resulting in discrimination even in mental health care settings (Audu et al., 2013). Some studies suggest that people with a mental illness may be discouraged from seeking treatment for their physical health issues. They may receive lower quality medical care (Desai, Stefanovics and Rosenheck, 2005; Druss et al., 2011). They are significantly less likely to receive important basic health checks (Roberts et al., 2007). Physical symptoms experienced by the person with mental illness may be wrongly attributed to the mental illness itself (Disability Rights Commission, 2006; Harris and Barraclough, 1998; Jones, Howard and Thornicroft, 2008). In general, response to mental illness tends to be different than it would be to any other physical disease (Dingfelder, 2009).

Power and the stigmatization process

Social stigma has been described as consisting of stereotypes, prejudice, and discrimination occurring in a situation where there is a power difference (Rusch, Angermeyer and Corrigan, 2005). Link and Phelan (2001) suggest that a power imbalance is necessary in order for the four elements (labeling, stereotyping, separation, and status loss and discrimination) of the model to become stigma. Power is not a separate element, but an

underlying current that affects all the other elements. A power difference occurs when those with mental illness have less social power than the stigmatizers. Stigmatization influences the discriminatory behavior and social context in which the power group interacts with people with mental illness (Corrigan, 2004a). Some groups holding the power to stigmatize include employers, landlords, health care professionals, policy makers, and the media. Link and Phelan (2014) use the term ‘stigma power’ to refer to instances in which the stigmatizers achieve their aims with respect to the exploitation, control, or exclusion of others.

A better understanding of the role that power plays in creating stigma can help us address some of the mechanisms that perpetuate it and make it difficult to disrupt. Many conceptualizations of stigma have focused on an individual or micro-interaction understanding of the process without adequately addressing the interaction with structural systems. Link and Phelan’s (2001) discussion of power is centered on the political, cultural, and structural power necessary to enact significant societal consequences because of a stigmatized identity. They propose that a group without power cannot stigmatize a dominant group because it does not control the social institutions required for the stigma to take effect. The focus on the structural supports that make stigma possible is the most innovative aspect of the Link and Phelan model. This theoretical development has earned the model praise from authors who consider power to be a crucial element that had been overlooked in studies of stigma (Green et al., 2005; Maman et al., 2009; Rutledge, Neil, Jacqueline and Theresa, 2009). However, as other authors caution, this model seems to dichotomize groups into powerful or powerless, dominant or subordinate, and these dichotomies can oversimplify intricate interactions without considering the power of resistance or the complexity of intersecting identities (Alvarado-Chavarría, 2012).

Treatments

Traditional Treatments and Smart People (Healers)

Indonesia is a multi-ethnic country and traditional treatments have a long history as a part of everyday life. Traditional treatments in Indonesia include the elements of an original Malaysian (proto-Malay) culture which were eventually augmented and modified by the introduction of Hindu, Muslim, some aspects of Chinese culture, and Christianity. All of these have merged into and been absorbed by the strata of Indonesian cultures (Hawari, 2001; Salan and Maretzki, 1983). These treatments play a key role in Indonesian healthcare and they are widely sought by Indonesian people to meet their mental health treatment needs (Faizal, 2012).

Many people in Indonesia continue to believe that mentally ill patients are possessed by devils, demons or spirits. Many still attribute mental illnesses to spiritual attacks, or as punishment for evil doings or illicit psychoactive substance use, among other things (Audu et al., 2013). Among the native populations in Africa too, many still believe that mental illnesses result from demonic possessions (Okasha, 2002). This study also indicates that alternative treatments are the first choice of psychiatric patients and their families. One previous study in Indonesia has demonstrated that most psychiatric patients have used alternative healers before going to healthcare facilities for treatment (Hawari, 2001). A study from Jakarta indicates that 45% of patients with mental illness will seek alternative treatments first for an average of 8.5 years before going to a mental health facility (Keliat et al., 2011). As outlined earlier, patients or their families have several choices of traditional healers or "smart people." In Indonesia, many patients who end up in clinics and hospitals have consulted one or several indigenous healers (Bahar, Ramli and Hardiman, 1979;

Leimena and Thong 1979; Syiwu 1979; Westa, Ratep and Putu, 1981). In Africa, Abbo et al. (2009) also found that about 60% of Ugandans seeking traditional healing practices had at least one diagnosable current mental illness and the majority had moderate to severe symptoms. Also, traditional healers were the first place where Ethiopians sought treatment for mental illness (Girma and Tesfaye, 2011), and in South Africa, they were key to patients and families in gaining understanding of the psychological experience and in obtaining access to social support structures (Myers, 2010). However, little recent literature discusses specifically the prevalence of paranormal beliefs or the psychiatric interpretation of subjective paranormal experience (Dein, 2012), although some studies have found that paranormal experiences do not help in treating mental illness (Goulding, 2004).

This study has demonstrated that many Indonesians who seek help from traditional healers for their treatment are also treated violently by them. People with already poor resources are ruthlessly exploited (Goffman, 1963). The WHO (2001) indicates that many times patients are ignored, isolated, or treated with rituals rather than with appropriate medications.

Modern treatments

Developing interprofessional approaches to delivering patient-centred care has received international interest from health care policy makers, practitioners, and researchers (Fox and Reeves, 2015). In health care settings with patient safety issues and increasingly complex health care needs, health professionals must be able to work in collaborative practice models (interprofessional teams) to ensure consistent, continuous, and reliable care (Chan and Wood, 2010). Inter-collaborative practice, which is also a model used at the RSMM Bogor, is designed to promote the active participation of each discipline, including medical doctors,

nurses, nutritionists, laboratory staffs, rontgen (X-ray) and physiotherapists, to provide the best possible care to patients. These professionals work together in a collaborative practice in providing services to the patients. As shown in the previous chapter, treatments provided at the psychiatric hospital can also be highly problematic.

Despite the goals of deinstitutionalization to treat mentally ill patients in their communities, mental health care is primarily carried out in institutions in many developing countries. For example, approximately 56% of mental health care still takes place in an institutionalized setting in South Africa (WHO and Ministry of Health South Africa, 2007). Most psychiatric care in Indonesia is also institutionally based.

However, there are some community programs in Indonesia that have the potential to enhance care of the mentally ill. Community Mental Health Nursing (CMHN) supports people with mental illness in a community setting, instead of in a psychiatric hospital (Keliat, 2013, Keliat et al., 2011). The goal of CMHN care services is to provide much more than just outpatient psychiatric treatment services; it also aims to include supported housing with full or partial supervision, local primary care medical services, Puskesmas, and self-help groups for mental health (Keliat and Akemat, 2004; Keliat et al., 2011). One problem related to these services in Indonesia is funding. In most low- and middle-income areas, community-based care requires additional fundng; not only are resources scarce for mental health, they are also inequitably distributed between countries and regions and within communities (Saxena, Thornicroft, Knapp and Whiteford, 2007).

The CMHN consists of community mental health nurses who have had assertive community training (ACT). ACT, a transdisciplinary team approach to provide treatment and rehabilitation to adults with severe and persistent mental illness, has been widely

implemented in Great Britain and other European countries (Killaspy et al., 2006; Manthey, Blajeski and Monroe-DeVita, 2012). It aims to reduce admissions to hospitals and to help patients stay in contact with mental health services in order to live as independently as possible in the community (Burns and Santos 1995; Rasmun, 2001). ACT in Indonesia is a partnership program among the RSMM Hospital, Community Mental Health Nurses (CMHN) and *Puskesmas* (Azizah, 2011; Keliat, 2013).

This study has shown that nurses routinely conduct "dropping" – taking patients who are ready for discharge back to their homes even if families have not accepted them (Keliat, Mustikasari and Panjaitan, 2003; RSJP Bogor, 1996). However, after discharging patients from the psychiatric hospital, nurses regularly visit them on an out-patient basis in their home. Nurses are the largest professional provider of health care services in the home setting, and at least one study has suggested that they have lowered health care costs (Marek and Baker, 2006). A study in Japan found that home visits by mental health nurses can contribute to positive mental health and social changes for women with post-partum depression (Tamaki, 2008).

This study indicates that even when patients are admitted to hospital, they are also enduring involuntary treatments, which include being forced to take medication, put in restraints or in seclusion, and being stripped. As Hawari (2001) has pointed out, these measures can only be appropriate if there is a serious and immediate safety threat, since enforcing treatment is traumatic and humiliating to patients, and tends to confirm false stereotypes about people with mental illnesses being inherently dangerous (Daulima, 2014).

Families' / relatives' care and support

Mental illness has an impact not only on patients but also on their families (Aziz, 2003; Chang and Horrocks, 2006; Daulima, 2014; Steele, Maruyama and Galynker, 2010). As many researchers have shown, relatives play an important role in supporting a patient with a mental illness; they can influence positively a patients' prognosis and help avoid relapsing, reducing the rates of psychiatric admissions and episodes of self-harm (Berry, Thornicroft and Szmukler, 1997).

Previous studies have examined the emotional responses of parents and siblings to family members with a mental illness (Leff and Vaughn, 1985; Vaughn and Leff, 1976). Approximately 50 to 80% of persons with schizophrenia and related psychotic disorders live with or have regular contact with a family (Gibbons, Horn, Powell and Gibbons, 1984; Lehman and Steinwaches, 1998), but families of these patients have a higher level of burden (McDonell et al., 2003).

Caring for someone with a mental illness involves a significant expenditure of time, energy, and money, and families are often asked to undertake tasks that may be unpleasant, uncomfortable, psychologically stressful, and physically exhausting (Daulima, 2014; Schulz and Martire, 2004; Yosep, 2009). They can suffer a significant amount of strain and difficulty, including financial problems (Azizah, 2011; Baronet, 1999; Magliano et al., 2002; Ohaeri, 2002). Adding to their burden is the shift to community care, which has made it increasingly difficult to hospitalize patients (Dyck, Short and Vitaliano, 1999; Effendy, 1995). Families who have had to deal with conflict-related trauma are more likely to reject their relatives, not surprisingly leading to poorer mental health outcomes (Kohli et al., 2014). Stigma can be a problem; especially where family members are blamed for the illness and

patients may experience feelings of shame (Daulima, 2014; Larson and Corrigan, 2008; Wahl and Harman, 1989). Mentally ill people in Indonesia are often avoided or abandoned by their families. As was shown, the shame, fear, and anger that families with a mentally ill relative experience create large problems in providing care, very often reducing the patients' participation in treatment and their chances of recovery. Also, family members in Indonesia are not adequately recognized for their contribution to mental health care nor do they have adequate information regarding the problem, treatment, or available resources (Daulima, 1999; Yosep, 2009).

Community-based care

The results of this study indicate that the social participation of Indonesian people with a mental illness is limited. Community members too experience a burden of care with these patients, and the mentally ill feel very clearly a lack of social acceptance. Little attention is paid to them and they are seldom included in community activities. A lack of social support increases the sense of isolation often experienced by those with a mental illness (Daulima, 2014; Keliat, 1996; Yosep, 2009). People with strong social support networks recover more easily (Corrigan and Phelan, 2004). Social participation can provide social identity and security for the patients, and those who perceive that they have good community support develop better coping skills (Daulima, 2014; Keliat, 2013; Rogers, Anthony and Lyass, 2004).

Saxena et al (2007) have found that only about 52% of low-income countries offer community-based mental health care programs, compared to about 97% of high-income countries. This study has found that there is very limited community-based care available for people with a mental illness in Indonesia. Although CMHN is available in some areas,

community-based care is only available in big cities such as Jakarta, Bogor, Surabaya, Semarang, Mataram and Jogjakarta (Azis, 2003; Effendy, 1995; Keliat, 2013; Yosep, 2009). According to Saxena et al. (2007), scarcity of available resources, inequities in their distribution, and inefficiencies in their use pose the three main obstacles to better mental health, especially in low-income and middle-income countries.

Restrictive measures

According to some estimates, nearly 0.5% of Indonesians (more than 1 million people) suffer from severe mental disorders, many of which go untreated due to the lack of professional mental health care in many provinces. This in turn results in many of them, about 18,800 Indonesians from mostly rural areas, being restrained and enduring seclusion, or what is known as *pasung* (Daulima, 2014; Keliat, 2013). As this study has demonstrated, *pasung* is used because both family and community members are ashamed and afraid of the mentally ill and the perceived (and sometimes real) potential for violence. Restraint and seclusion obviously have a negative impact on patients, with their use having the potential to cause both physical and psychological trauma (Daulima, 2014; Doloksaribu, 2008; Haimowits, Urff and Huckshorn, 2006; Keliat et al., 2011), with no benefit from long-term behavioural changes. It may even cause patient deaths, either directly (Berzlanovich, Schöpfer and Keil, 2012) or through suicide (Haimowits, Urff and Huckshorn, 2006).

This study has shown that in the RSMM mental hospital, nurses too continue to use restraint and seclusion for people who suffer from mental illness. As some research has found, it is used frequently in mental health services to manage aggression, damage to property or self-harm (Daulima, 2014; Doloksaribu, 2008; Hawari, 2001; Richter and Whittington, 2006), although managing violence and aggression in this way is said to be

reactive and controlling (Duxbury, 2002; Effendy, 1995, Rasmun, 2001; Sailas and Wahlbeck, 2005). Staff that is worried about patient aggression may try to manage their fears with physical methods, such as seclusion and restraints (Foster, Bowers and Nijman, 2007). Sequeira and Halstead (2004) also state that nurses responsible for implementing restraint and seclusion often are psychologically affected. They sometimes become skeptical about any measures for aggressive mentally ill patients (Amalia, 2010; Keliat et al., 2011; Kontio, et al., 2010). In violent situations, nurses may even try to dissociate themselves from patients (Farrell, Bobrowski and Bobrowski, 2006; Holmes, Perron and O'Byrne, 2006; Keliat, 2013; Kindy, Petersen and Pakhurst, 2005) to the point of becoming passive caregivers.

The humanitarian, ethical, and legal issues associated with the use of these restrictive interventions make them highly controversial management strategies. Many authors suggest that physical restraint should only be used as a 'last resort' to manage unwanted or harmful behaviours (Daulima, 2014; Doloksaribu, 2008; Keliat et al, 2011, Keliat, 2013; NICE, 2005). Each of these interventions has rare but potentially fatal complications (Azizah, 2011; Holmes, Perron and Guimond, 2007; Keliat, 2013; Sailas and Wahlbeck, 2005). Some researchers argue that special observation may be a better method and an alternative to more restrictive measures (Daulima, 2014; Holmes et al., 2012; Keliat, 2013).

Barriers to accessing mental health treatment

Over 450 million people worldwide are estimated to be suffering from a mental illness but only a small proportion of these people receive any form of modern treatment (WHO, 2003). Government spending on mental health in most low- and middle-income countries is far lower than is needed and the poorest countries spend the lowest percentages

of their overall health budgets on mental health (Saxena et al., 2007). Twenty-five percent of countries fail to provide disability benefits to patients with mental disorders, and one-third of the world's population lives in countries that allocate less than 1% of their health budget to mental health (WHO, 2012). Thirty-one percent of countries do not even have money budgeted for mental health services (Saxena et al., 2007).

Common barriers to mental health care access include limited availability and affordability of mental health care services, insufficient mental health care policies, lack of education about mental illness, and stigma. As this study has shown for Indonesia, economic issues are a significant barrier to accessing treatment for people with a mental illness, since many assume that hospital treatment is expensive, and, as the nurses reported, people still believe that the hospital will not accept patients who suffer from mental illness. Most of the mentally ill are poor, and only some, especially in the rural areas, know about or have Jamkesda or Jamkesmas, the two forms of health insurance available to them. The costs involved in travel, coupled with the long distances to reach services, contribute to these barriers. Therefore, improved transportation, flexible fee-based services, and integration with community resources would improve access to care and the overall health status for people with mental illness.

In many low-and middle-income countries, high prices for medications pose significant financial barriers to patient care (Saxena et al., 2007). As well, Benkert et al., (1997) found that psychiatric medicines were generally not well accepted because they were believed to cause more severe side effects than cardiac drugs. Similarly it is often believed that psychiatrists tend to use medications rather than psychological treatments, and that these drugs have unpleasant or even dangerous side effects (NICE, 2004). As this study of the

RSMM Bogor revealed, several patients and their families believed medications for mental illness could make patients drug dependent.

Lack of knowledge and information about mental illness and its treatments are also barriers to accessing healthcare facilities in Indonesia. As others have found, families or relatives do not receive the information that they need to care for their relatives with a mental illness (Pickett-Schenk, Lippincott, Bennett and Steigman, 2008) and they often lack the necessary skills (Heru, 2000; Pollio et al., 2006; Solomon et al., 1997). Saxena et al., (2007) has indicated that limited knowledge can prevent people from recognizing mental illness and seeking treatment; poor understanding of mental illness also impairs families' abilities to provide adequate care for their sick relatives in low- and middle-income countries. In Africa, many believe that mental illness is caused by demonic possession; therefore, many individuals fear social ostracism and they tend to keep their mental illness secret instead of seeking medical attention (Okasha, 2002).

Perhaps the greatest barrier to treatment is the stigma associated with mental illness that can be found in all aspects of Indonesian society. Many authors indicate that the stigmatization of mental illness represents a serious barrier to accessing medical and psychological treatment (Wisdom, Clarke and Green, 2006). Stigma impedes patients from seeking treatment (Corrigan, 2004b), can lead to them discontinuing treatment early (Kreyenbuhl et al., 2011) and can result in psychiatric re-hospitalization (Rüsch et al., 2009). Myths and misconceptions about mental illness contribute to the stigma, which leads many people to be ashamed and contributes to their reluctance to seeking help. Gater et al., (1991) and Nguyen (2003) indicate that traditional beliefs attributing mental illness to sinful behaviour and that portray patients as dangerous lead to feelings of shame within the

mentally ill and others to fear them.

It is believed that the negative reactions and societal rejection associated with mental illness are part of the reason that a majority of mental illness sufferers actively choose not to seek help (Link, Cullen, Frank and Wozniak, 1987). For patients themselves, admission to a psychiatric inpatient treatment centre can be experienced as disempowering and stigmatizing (Rüsch et al., 2014). One study found that patients with schizophrenia who were involuntarily admitted expressed feelings of humiliation (Azizah, 2011; Birchwood, Mason, Macmillan and Healy, 1993; Rooske and Birchwood, 1998). Svindseth, Hatling and Dahl (2007) also found significant associations between humiliation and the patients' feeling that the admission was not right. Similarly, in a study of participants who were spouses and parents of those with a mental illness, about half indicated attempts to mask it (Byrne, 2000). As this study has indicated, feelings of shame prevented many Indonesian patients and their families from seeking help; many were afraid of being labelled by others as mentally ill, and were ashamed to be put in a ward together with others with a mental illness.

Negative experiences with service providers or systems may also prevent patients and their families from seeking help (Swartz et al., 1999). Mental health professionals themselves are a significant source of public stigma (Schulze, 2007) and people with a mental illness may feel unwelcome because of staff attitudes (Hodges, Inch and Silver, 2001; Lauber et al., 2006; Ucok et al., 2004). In addition, healthcare workers may lack skill in diagnosing mental illness and public health facilities may be limited in serving sufferers (Rudi, 2012). Patients may have more difficulty in obtaining a primary care physician (Bradford et al., 2008; Druss and Rosenheck, 1998) or medical practitioners may diagnose and treat people with a mental illness differently.

Violence

The association of mental illness with violence or danger is a major cause of stigma for sufferers. In this study on Indonesian patients, the results indicate that patients are often portrayed as violent, both in their family situations and in their communities. As far as psychiatric patients are concerned, violence is rarely directed towards others. On the contrary, violence is often exerted towards oneself. In effect, suicide is often attempted by patients as the ultimate effort to solve their problems (Keliat, 1991). Self-directed violence includes suicidal thoughts, attempted suicides or ‘deliberate self-injury,’ and completed suicides. Self-directed violence is often a coping mechanism that provides temporary relief of intense feelings such as low self-esteem, anxiety, stress, or a sense of failure from living with mental illness. In Indonesia, religious beliefs forbid suicide or self harm, often making the patients feel powerless. In some countries, even attempted suicide is a criminal offence punishable by law, and is therefore often a secretive act surrounded by taboo that may be unrecognized, misclassified, or deliberately hidden in official records of death (WHO, 2002a).

Many authors state that suicide ratios are higher with people with serious mental illness, with 18-55% of this group reporting suicide attempts (Fenton, McGlashan, Victor and Blyler, 1997; Harkavy-Friedman et al., 2003; Tarrier, Barrowclough, Andrews and Gregg, 2004; Tondo, Isacsson and Baldessarini, 2003). The risk of committing self-harm, or threatening to do it, is especially elevated among those with schizophrenia (Fox and Hawton, 2004; Keliat, 1999; Yosep, 2009). In the UK, a report from the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCI) found that suicide by mentally ill patients was on the rise, with 1,333 deaths in 2011 (University of Manchester,

2013). Women who had experienced physical or sexual violence reported higher levels of emotional distress than other women and were more likely to attempt suicide (WHO, 2005b).

As this study has shown, patients with a mental illness may also be violent toward healthcare professionals. Patient violence has become an increasing concern (Azizah, 2011; Davison, 2005; Kusumawati and Hartono, 2010; Luck, Jackson and Usher, 2006; Onwumere et al., 2014; Rasmun, 2001). Both physical and verbal violent behaviors are common occurrences in hospitals and other mental health settings (Duhart, 2001; Jansen, Dassen and Jebbink, 2005; Keliat, Mustikasari and Panjaitan, 2003; Love and Morrison, 2003; Riyadi and Purwanto, 2010). Violence is the most negative behavior conducted by mentally ill patients in psychiatric hospitals (Keliat, Mustikasari, Panjaitan, 2003). It is estimated that in the US, people who work in mental health settings become victims of violence three times more than people who work in general medical settings (Bilgin and Buzlu, 2006). Also, 40 to 50% of psychiatry residents will be physically attacked by a patient during their four-year training program (Petit, 2005).

Among healthcare professionals, nursing is one of the most likely to be the target of violent acts (Anderson, 2002; Davison, 2005; Holmes, Kennedy and Perron, 2004; Inoue et al., 2006; Lawoko, Soares and Nolan, 2004); some have found that nurses are 16 times more likely to experience this type of violence than any other worker (Elliot, 1997). Some studies even indicate that most nurses experience verbal or physical abuse during their careers (Hesketh et al., 2002; Inoue et al., 2006; Landy, 2005). For example, violence against nursing staff in the UK was consistently high, with up to 86% of nurses affected (Healthcare Commission, 2005). In Japan, a survey of 225 psychiatric nurses found that 62% had been

abused (Inoue et al., 2006). It is important to state that violent behaviour in patients can be influenced by environmental and contextual factors (Duxbury, 2002; Effendy, 1995). Unclear policy and guidelines, overcrowding, poor ward design, inexperienced staff, poor staff retention and a lack of information sharing all contribute to violent or aggressive behaviour (Daulima, 2014; Doloksaribu, 2008; Healthcare Commission, 2005; Keliat, 2013; NICE, 2005).

According to many of the Indonesian patients, however, their violent behaviour stemmed from the violence they experienced from others. Patients with a mental illness are at substantially increased risk of domestic or family and sexual violence (Khalifeh et al., 2015). One study in the US finds that people with serious mental illnesses are 3.7 times more likely to have experienced physical abuse by their parents or to have grown up witnessing physical fighting between their parents, compared to people without a mental illness (Elbogen and Johnson, 2009).

Much of the violence against the mentally ill is also found out in the community. People with mental illness are often exposed to torture or other cruel, inhumane, or degrading treatment, including sexual exploitation and physical abuse (WHO, 2005c). Rates of victimization among people with mental illness vary from place to place (Honkonen et al, 2004). A study in the US reported that the violent victimization rate of those with a mental illness was double that of the controls (Silver, 2002). A Greek study found that mentally ill people report being victims of crime and discrimination more frequently than healthy controls (Katsikidou et al., 2012). In England, Hodgins et al., (2007) found that many of the men (57%) and the women (48%) had been the victim of aggressive behaviour in the preceding 6 months. In Canada, a study indicated that up to 60% of inmates have reported

some level of victimization in prison (Brink, Doherty and Boer, 2001; Robinson, Muirhead and Lefaive, 1997). In Australia, 18% of mentally ill patients had been abused in the year preceding the study, three times more than in any other population group (Chapple et al., 2004). In Taiwan, the abuse of patients with severe mental illness is higher than in the general population (Hsu et al., 2009).

According to Teplin et al., (2005), the stress and trauma of being victimized can heighten an individual's sense of vulnerability and anxiety, which can exacerbate symptoms of the mental illness, increase the likelihood of homelessness, and diminish quality of life. In addition, the psychological consequences of victimization can be serious in terms of relapse of mental illness (Azizah, 2011; Goodman, Dutton, and Harris, 1997; Keliat, 2013; Lam and Rosenheck, 1998) and social withdrawal (Cullen et al., 2011).

Studies have suggested that the mentally ill have contributed little to the rates of violence, and further, that the general population greatly exaggerates its risk (Institute of Medicine, 2006). In addition, violent behavior will only appear to be more common when other risk factors are present, such as substance abuse or dependence, a history of violence, juvenile detention or physical abuse, and recent stressors such as being a crime victim, getting divorced, or losing a job (Elbogen and Johnson, 2009). Research also indicates that the link between violence and mental illness is often promoted by the entertainment and news media. Most news accounts portray people with mental illness as dangerous (Wahl, 1995). Furthermore, inaccurate and stereotypical representations of mental illness exist in films, music, novels, and cartoons (Wahl, 1995), with few positive stories showcasing the recovery of people with even the least serious mental illnesses (Wahl, 2003).

Fear

Fear is a negative emotion elicited by a relatively specific stimulus which is perceived as dangerous or harmful. It has become the invisible companion of risk (Furedi, 2006). Mental illness is often associated with the fear of the potential threat of patients with such illnesses (psychophobia). Participants in this study have shared their feelings and experiences of fear brought about by interactions with their families, community, and often, the healthcare professionals with whom they came in contact. Fear of the mentally ill can result in insufficient treatment to meet a patient's physical and psychological needs (Keliat, 1996).

Patients' Fears

A close relationship exists between the violence experienced by the patients and the fear that they have. According to Dingfelder (2009), feelings of fear can even contribute to violence and it makes mental illness far more severe by discouraging treatment and promoting social isolation. In Indonesian society, those whose behaviour disturbs others will be obligated to have medical treatment, although it is important to regard the use of forced treatment as reflecting a failure in service and to reform systems accordingly. Many of the patients interviewed were forced by their families and community members into seeking help for their mental illness; they were either taken unwillingly to alternative treatment sites where shamans and other smart people aggressively tried to rid their bodies of spirit possession, or they were involuntarily admitted to the RSMM where they may have been restrained or put into seclusion if they were considered violent.

This study finds that patients (and their families) were often afraid of the psychiatric medication they were prescribed. As other studies have shown, people with a mental illness believe that psychiatrists tend to use medications rather than psychological treatments, and

that these drugs have unpleasant or even dangerous side-effects (National Institute for Clinical Excellence [NICE], 2004). A study in Germany found that psychiatric drugs were generally not well accepted because they were believed to cause more severe side-effects than cardiac drugs. The direct experience of contact with people taking psychiatric medications is limited, and so most people draw on other sources of information, mainly reports in the mass media, which give an overwhelmingly negative account of mental illness and its treatments (Benkert et al., 1997).

Study participants also feared the social rejection that having a mental illness brings. They were often abandoned in hospital by their family and socially isolated by their community if and when they returned. Discrimination and the stereotypes of people with a mental illness create a desire for social distance (Corrigan et al., 2003). Many patients report feeling lonely, losing contact with friends and family, losing their jobs and being relegated to lower positions in their workplace if they did keep their employment (Svab, 2012). People who experience mental illness will make considerable efforts to hide this aspect of their lives (Lee, 2002).

Fear toward the patients

The participants in this study indicated that family members and relatives feared their family members who were suffering from a mental illness, primarily based on the potential for violent behaviour and the unpredictable nature of their distress (Araujo and Borrell, 2012; Bathje and Pryor, 2011). Goffman (1963) showed that attributes ascribed to people with mental illness led to this stereotypical picture of unpredictability and dangerousness. Multiple studies have since suggested that stigma associated with mental illness creates a fear of being given this dangerous label (Daulima, 2014; Keliat, 1999; Hayward and Bright

1997; Kent and Keohane, 2001). Cullen and Cullen (1978) and Scheff (1984) indicate hallucinations and delusions in schizophrenia tend to be perceived as threatening, thereby provoking fear and discomfort in others. One in four Canadians are afraid to be around someone with a serious mental illness (Canadian Medical Association, 2008). In addition, many perceive that the mentally ill pose a threat to public safety (Canadian Alliance on Mental Illness and Mental Health, 2007; Jorm & Griffiths, 2008). According to one American report, 61% of the population believed that a person diagnosed with schizophrenia would be dangerous to others (SAMHSA, 2010) and 33% think that people with depression are likely to commit violent acts (Phelan and Link, 2004).

The media has certainly influenced people's negative attitude toward mental illness. The majority of stories about mental illness focus on the most serious mental disorders, highlighting bizarre symptoms, dangerous behavior, and criminal activity (Hayward and Bright, 1997; Stuart, 2006; Wahl, 1992). For example, according to Phelan and Link (2004), as many as 75% of stories dealing with mental illness focused on violence, and 72% of the mentally ill characters on television were presented as dangerous (Stout, Villegas, and Jennings, 2004). An American study has reported that reading a newspaper article on a violent crime committed by a mental patient led participants to have increasingly 'negative attitudes toward people with mental illness' (Thornton and Wahl, 1996).

Nurses at the RSMM Bogor admitted to being fearful of mentally ill patients, with some considering them to have a contagious illness. Other studies have pointed out that the fear and repulsion experienced by nurses can greatly influence the nurse-patient relationship, preventing adequate and appropriate nursing care (Effendy, 1995; Holmes and Federman, 2003; Holmes, Perron and O'Byrne, 2006; Jacob, 2010; Keliat and Akemat, 2004; Kindy,

Petersen and Pakhurst, 2005; Peternelj-Taylor, 2004).

Constructing cursed citizens

Patients' Feelings

The participants in this study often expressed feelings of shame, talking about how the label of 'crazy' people made them feel useless and powerless. They believed that they were abandoned and neglected by others because of a mental illness, often mentioning that family members or relatives just put them in the hospital and never came to visit. They avoided social interaction for fear of being rejected, humiliated, or ridiculed. They were also afraid to meet other people – afraid of rejection by friends and by community members. They also talked about suffering discrimination in their professional lives as well, being denied promotions in their work or even a job in the first place.

Throughout history, people considered different have been labeled and discriminated against for their mental health states. From the labels of 'moron' and 'idiot' to 'psycho' and 'crazy,' people suffer from mental illnesses have been deemed socially undesirable and have therefore been stigmatized (Rose, Thornicroft, Pinfold and Kassam, 2007). People with mental illness internalize these labels, leading to a negative sense of self-worth and feelings of hopelessness for the future (Corrigan, 1998; Holmes and River, 1998; Keliat, 1999; Link and Phelan, 2001).

Social isolation in people with mental illness is common and has a significant impact on their wellbeing, recovery, and community participation (Keliat, et al., 2005; Rasmun, 2001). The mentally ill are the most rejected among disabled groups (Albrecht, Walkeer and Levy, 1982; Link et al., 1987). Stigma creates a vicious cycle of alienation and discrimination that leads to homelessness (Bachrach, 1992) and social isolation (Amalia,

2010; Azizah, 2011; Keliat, 1999; Leary, Johnstone and Owens, 1991). In patients with bipolar disorders, 50-75% of them indicated that their relationship with family members and friends was severely and adversely affected due to stigmatization (Lish et al., 1994).

A person with a mental illness may feel the effects of social rejection, isolation, and discrimination for most of his or her life (Corrigan, Markowitz, and Watson, 2004; Link et al., 2001; Nelson, 2002). Many mentally ill people will avoid situations or give up opportunities because they fear the consequences of being labeled as mentally ill (Link, 1982). Goffman (1963) has suggested that to avoid discrimination and rejection, persons with a mental illness may limit their social interactions to individuals who are similarly stigmatized or who are aware of and accept the stigma (e.g., family members). They anticipate rejection and develop coping strategies such as being secretive about their illness or withdrawing from social interaction (Link et al., 1987, 1989).

People with a mental illness are humiliated if the symptoms of their illness are displayed in front of others, and a central element of humiliation is the loss of the status (Torres and Bergner, 2012). According to Lazare and Levy (2011), "humiliation is the emotional response of people to their perception that another person or group has unfairly or unjustly lowered, debased, degraded, or brought them down to an inferior position, that they are not receiving the respect and dignity they believe they deserve" (p. 746-747). A US study found that 68% of Americans do not want someone with a mental illness marrying into their family and 58% do not want people with mental illness in their workplaces (Dingfelder, 2009).

One of the many consequences of having a mental illness is homelessness, as this study also found. Many people with mental illness remain homeless for longer periods of

time because they have less contact with family, relatives, and friends. According to the National Resource and Training Center on Homelessness and Mental Illness (2003) in the US, approximately 20-25% of the single adult homeless population suffers from some form of severe and persistent mental illness.

Family members

There is no doubt that the families of those with a mental illness are affected by the condition of their relatives. Larson and Corrigan (2008) describe a concept called ‘family stigma’ – the negative impacts on family members of persons with mental illness. Connection is the one basic element needed for a relationship to thrive between patients and families (Daulima, 2014; Effendy, 1995; Rasmun, 2001). But very often families and relatives lack support if someone in the family has been diagnosed with a mental illness. They may feel uncomfortable if patients are at home – afraid that patients will be violent. They sometimes distance themselves from patients if they are in hospital, give up visiting if the patient is in hospital for a long time, or simply abandon them to the streets. One patient participant in this study was divorced by his wife because he suffered from a mental illness. Family rejection leads to reduced participation in treatment and a reduced level of recovery. It also prevents families from accepting their illness and taking responsibility.

A focus on family stigma may be necessary in order to lessen the negative consequences of the stigma related to mental illness. Family members, especially parents, are often blamed for their mentally ill relative, which may lead to feelings of shame themselves. One reason for shame is caused by a lack of knowledge related to mental illness. Families may believe that mental illness is caused by demons, or that it is contagious or hereditary. According to one patient participant, families know where to go for treatment of

a physical illness but often do not if the problem is related to a mental illness. The family can also be ashamed if they are well known in society. The higher the status of the family, the greater may be the reluctance to discuss the issue, regardless of educational achievement (Estroff, Lachicotte, Illingworth and Johnston, 1991). The value placed on family reputation may be so strong that the family will not discuss mental health problems even with a mental health professional. Rich families may hide patients in *pesantren* or foundations, while others isolate patients in their homes or in the jungle. The act of hiding a person with a mental disorder only strengthens the vicious circle of prejudice (Hawari, 2001).

Community

Studies of public attitudes toward people with mental illness have found that many people have concerns about living, working, or socializing with people with a mental illness (Keliat et al., 2011; Link et al., 1999; Martin, Pescosolido & Tuch, 2000). Feelings of fear make mental illness far more severe by discouraging treatment and promoting the social isolation of mentally ill people (Dingfelder, 2009). This study has demonstrated that patients are often socially isolated in their communities, and many of them believe they are not accepted because they are no longer considered productive members of society. They often have difficulties finding employment, renting apartments, and being included in community activities (Link and Phelan, 2001). Therefore, many patients are happier to remain in hospital.

Government and media

The Indonesia government tends to have negative attitudes toward people with a mental illness. For example, many departments refuse to hire patients or ex-patients. Some nurse participants indicate that there is little government-managed care for patients with

mental illness; crisis response services such as crisis lines, mental health teams, and hospital emergency wards are limited in scope and are often not well integrated.

Indonesian media and entertainment play a key role in shaping public opinions about mental health and illness. Entertainment frequently features negative images and stereotypes about mental illnesses, and these portrayals have been strongly linked to the development of public fears concerning individuals with mental health conditions (Arboleda-Florez, 2003). People with mental illness as a whole are portrayed as violent and dangerous people that have severely disturbed thought processes and therefore have unpredictable behavior and should be feared (Ross and Goldner, 2009). When the media focuses on rare, tragic events that involve someone with a mental illness, it increases fear (Kobau et al., 2010). Television portrayals do little to convince the public that individuals with mental illnesses do recover, and become active and productive members of society (Stuart, 2006). A popular Indonesian TV program 'Opera Van Java', insults and parodies mentally ill people. Analyses of films have identified three themes that contribute to misconceptions about people with mental disorders: they are homicidal maniacs who need to be feared; they have childlike perceptions of the world that should be marveled at; or they are responsible for their illness because they have weak character (Corrigan and Watson, 2002). In a study of 34 Disney movies, 85% of them disparage mental illnesses by portraying their cartoon characters under such labels as nuts or crazy (Parmar, 2004). Even healthcare professionals who interact with people experiencing mental illnesses may be the victims of negative media portrayal. Studies suggest some people may have warped perceptions of psychiatrists; female clinicians are more likely to be portrayed as sexualized and male clinicians as incompetent in American cinema (Stout, Villegas, and Jennings, 2004).

Nurses

Nurses themselves sometimes suffer stigma from working with the mentally ill. As this study has suggested, they believe that they are insulted by other people and they feel isolated both from society at large as well as the general nursing profession. The stigma towards healthcare professionals results in disparities in access, treatment, and outcomes (De Hert et al., 2011; Phelan and Basow, 2007). Negative stereotypes portray mental health professionals as eccentric buffoons, evil minded, and repressive agents of a social system and in the case of female psychiatrists, as loveless and sexually unfulfilled (Gabbard and Gabbard, 1992). In one study conducted in Singapore, about 60% of psychiatric nurses had been laughed at for working with psychiatric patients while 30% had been discouraged from joining the profession (Lai, Hong and Chee, 2001). Stigmatizing beliefs regarding mental health nursing discredit their valuable contributions and influence the needs of people who need to access mental healthcare services (Gouthro, 1999).

As indicated previously, some nurses have indeed been the victims of assault and verbal abuse. Although some nurses deny that working in a psychiatric hospital is dangerous – that the general public has a mistaken impression of the threats posed by patients – others do consider it hazardous (Azizah, 2011; Nursanti, 2006; Yosep, 2009) and that nurses who work there are assumed to face physical and psychological threats from their patients (Amalia, 2010; Hawari, 2001; Kusumawati and Hartono, 2010). Some believe that mental illness is a contagious disease, or that they fear ‘infection’ despite it being general knowledge that mental illness cannot be transmitted (Švab, 2012). Other nurses, particularly those not involved in caring for the mentally ill, make the assumption that a mental illness is

synonymous with being insane (Nursanti, 2006), leading to their viewing psychiatric or mental health nursing unfavorably (Izzudin, 2006)

Responses to Stigmatization: Patients

Self-stigma is described by Corrigan (2004) as the negative attitudes, attributes, feelings and emotions that the members of a stigmatized group project upon themselves. The patients participating in this study responded to the stigmatization of their mental illness in different ways. Many considered it a social disgrace and were ashamed of being put in the hospital. Some used violence either against themselves in attempts at suicide or they fought with their families, community members, and hospital staff; and often their violence was a reaction to the violence that they had experienced at the hands of others. Others became homeless. Still others denied that they were ill or failed to seek adequate treatment. Some patients only had social interaction with members of a support group for people living with mental illness. A possible reason behind their social withdrawal is that there were no longer any opportunities or social events taking place in that participant's life where they were accepted.

Responses to Stigmatization: Nurses

As this study has demonstrated, nurses also dealt with stigma and the mentally ill in various ways. Some admitted that they were somewhat afraid, fearing both the potential violent behaviour of their patients or the nature of the illness itself. They in turn felt they were discriminated against by other nurses in their profession, primarily because work in psychiatric hospital is considered dangerous. Sometimes they felt humiliated when they are labeled 'crazy' as their patients had been labeled.

The patients are often victims of these negative attitudes, enduring physical and

psychological abuse from the nurses and other hospital staff; they were sometimes put in seclusion or nurses shouted and snapped at them. Other stigmatizing attitudes were manifested through staff indifference, a limited use of the recovery approach, and a lack of individualized care. In this study, it was also possible that because patients were stigmatized by professionals, they might not have brought it up as an issue because of fear of further stigmatization.

Study Limitations

This study has limitations with regard to the methodology and its findings. The researcher's limited experience as an interviewer was another limitation. Interviewing mentally ill people is not easy. It is a challenge. Although many readings and some practice was done before the interviews started, the actual interview process was different. During the process, participants might have felt that the researcher wanted to hear particular information rather than feeling free to express what they actually felt. Study participants may have seen the interview process as a professional threat, regarding the interviews as being more like an investigation of them. It is also possible that the participants' fear of stigma limited their ability to fully disclose all their experiences. Although the participants were assured that the interviews were confidential, some may not have felt comfortable revealing or discussing particularly difficult experiences and, therefore, may not have been completely open and/or honest in their responses. Although the choice of constructive grounded theory method has allowed theoretical works to be added as dictated by the data collection, the analysis remains limited to the researcher's position in term of his experience in conducting this kind of data analysis.

Given that the study was limited to just 30 participants, it cannot be inferred that these findings are representative of all those with a mental illness. Data gathered was specific to each of the participant's experiences and is therefore not transferrable to the entire mentally ill population. Findings from this study may not be applicable for all mentally ill people in different populations. Additionally, the participants' ability to recall past events could be considered a limitation in this study based on the differences in the length of time since diagnosis, as people's perceptions of their experiences can change over time.

Study Implications

Implications for Nursing Practice

This study has found that treatment for mental illness in Indonesia is hampered by stigma and discrimination. The findings are relevant for mental health nurses who provide direct nursing care to their patients, as well as for other areas of practice where patients may be exposed to stigmatization.

Mental health nurses working with their patients should be urged to facilitate interventions to counteract internalized and social stigma through encouraging patients to participate in self-help and peer support groups, where individuals who have been diagnosed are able to talk openly among themselves without judgment. These efforts would help to empower, educate, and alleviate some of the effects of stigmatization. The study participants indicated that most of them did participate in *Terapi Aktifitas Kelompok* (group activity therapy) and that this therapy and the acquired skills contributed positively to their life satisfaction. This kind of therapy limits social withdrawal and minimizes feelings of isolation and alienation, but it needs to involve family and community members to help patients normalize the stigma of mental illness that surrounds them.

Being transparent about ones' mental illness may diminish the affective conditions related to the shame that may emerge. Nurses can employ strategies like role playing to effectively support their patients in disclosing a mental health diagnosis. Helping patients to educate themselves on the frequently asked questions and concerns that result from self-disclosure can help equip individuals living with mental illness to express themselves in a confident and informed manner. Nurses can help to assess patients' emotional readiness to come out about their diagnosis as timing is an important consideration in disclosing. They also can help their patients to determine whether they are prepared to potentially face social stigma or discrimination should they decide to disclose.

Nurse participants feel that mental illness stigma is an important topic both personally and for the nursing field. More effort needs to be undertaken to reduce the stigma of mental illness as perceived by the general public. Nurses supporting those living with a mental illness must consider their own position regarding the pathology and individualism of mental illness in association with their patients. Educating nurses about the social construction of mental illness and the impact of such on those who are labeled is important to recognizing the lived experience of stigma and its consequential effect on life satisfaction.

Nurses should also practice reflexivity in determining their own misconceptions, perceptions, attitudes, prejudices, and discriminatory behaviors. They must assess the implications of perpetuating derogatory stereotypes in order to effectively address the impact of social and internalized stigma on their patients' lives. It is also important to provide a societal discourse that challenges existing stigma and create a safe space for mentally ill patients, families, and community members to feel empowered to discuss their own feelings and concerns.

Stigma remains a clinical and social justice priority to provide ongoing support for people with mental illness, to develop and evaluate both general and more targeted anti-stigma interventions. Michaels, et al., (2012) propose anti-stigma initiatives with more tailored content for specific groups (e.g., police officers vs. general public) that may diminish the negative consequences of mental illness stigma by providing more concrete ways to help stigmatized people. Rüsch, Angermeyer and Corrigan (2005) provide three main anti-stigma campaign strategies to reduce the stigma attached to mental illness through protest, education, and contact.

The misconceptions about stigma are significantly prevalent among patients, families, communities, healthcare professionals, and government bodies in Indonesia. Stigma is of central importance to persons with mental illness, both to how they experience their illness and its consequences and whether they access available health services. An important effort is empowering patients to be able to live independently and productively and this effort can only succeed with optimal caring from family members and their communities. I believe that a well-designed anti-stigma initiative will help to diminish negative consequences of mental illness stigma in Indonesia. Efforts to understand the problems wrought by stigma and to develop programs that will diminish its impact will greatly advance the goals of people with mental illness.

This study has indicated that there is also a lack of information and knowledge, which is a significant barrier to treatment, and interventions targeted at improving public awareness about the causes and treatment of mental illness could reduce the delay in seeking treatment or would improve treatment outcomes. Early recognition of the signs and symptoms of

mental illness is important because early intervention is critical to restoring the mental as well as the physical and the social health of an individual (Girma and Tesfaye, 2011).

Implications for Nursing Research

The study findings provide useful material for future research directions with Indonesian people with a mental illness. First, based on these study results, the degree to which stigma exists may determine the rate at which one progresses through the various stages of recovery. More research is needed to measure the presence of stigmatization and how it changes or does not change over time from onset of symptoms to recovery. In addition, during the interviews some participants seemed to express a great deal of internalized stigma and its negative impact on their life satisfaction. More research in Indonesia is also needed to investigate this issue.

This study has not been focused on intra-familial stigma but more investigation is needed to look at how family members as participants contribute to perceptions of stigma experienced by their members who have a mental illness. This issue will be worth studying as it is documented that self-stigma in family members and relatives adds to their burden as caregivers. In addition, research needs to be conducted into public attitudes to mental illness as participants in the study reported experiencing stigmatizing attitudes from the public.

Furthermore, this study has not assessed structural discrimination occurring through government legal, social, and political systems. Further research is needed to investigate this kind of discrimination in Indonesia in order to improve mental health measures, education, and community services. Finally, it is not possible to generalize these study findings. Using one setting represents only a sample and not the entire spectrum of the population of adults with mental illness in Indonesia. The use of other mental health settings may produce

different important data.

Implications for Nursing Education

Education related to mental illness and stigma is still not a fundamental part of the psychiatric nursing curriculum in Indonesia. The study findings provide some useful materials and information to be incorporated into nursing education directed toward enabling current and future providers of mental health services to help people with mental illness in Indonesia. Given the possibility that nursing students will take care of people experiencing symptoms of mental illness, it is important to include a component on the stigma related to mental illness because of the potential that they will face stigma themselves by the general public, particularly if they find work as mental health nurses after they graduate. This kind of education needs to incorporate the politics of care (including institutional functioning and agendas) that directly affect nursing practice. Nursing students need to be conscious of patients' potential to affect the provision of nursing care. Nursing under threat may all too easily justify certain types of interventions (such as the use of restraint or seclusion) to the detriment of the nurse-patient relationship. It is in my hope that my future career will involve addressing the structural ineptitudes of the educational and mental health care system in order to help my students understand mental illness in Indonesian society.

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University Press.

Appendices



APPENDIX A

KEMENTERIAN KESEHATAN REPUBLIK INDONESIA
DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT dr. H. MARZOEKI MAHDI BOGOR



Jalan dr.Sumeru No.114 Bogor 16111 PO.BOX. 178

Telepon (0251) 8324024, 8324025, 8320467 (Hunting)

Number : DL.01.1.2/III.2/2307. /2013
 Subject : Research Permission

29 April 2013

To:

Mr. Muhammad Arsyad Subu

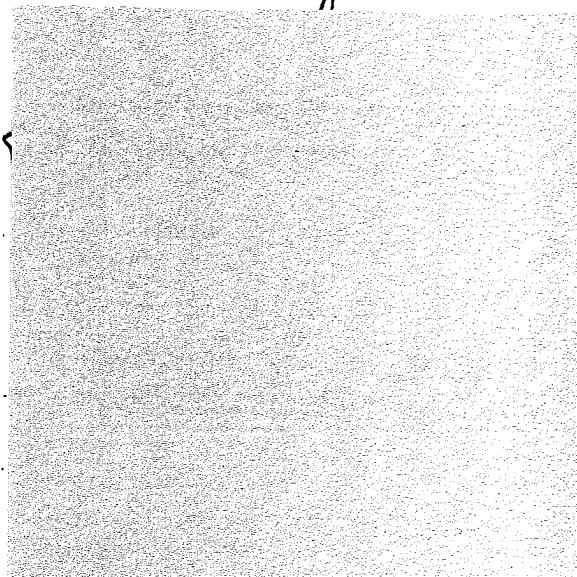
**Student: School of Nursing, Faculty Of Health Sciences University of
 Ottawa Canada.**

Dear sir,

Regarding your application to conduct your study, title: ***"Persistent Taboo:
 Understanding Mental Illness and Stigma Amongst Indonesian Adults through
 Grounded Theory"***,

1. I approve your application to conduct your study
2. Related to (number 1 above), we ask you to:
 - a. present your proposal to the staff of Educational, Training and Research Division
 (please adjust and coordinate regarding time and place for presentation)
 - b. accomplish your proposal with ***"Ethical Approval"*** from University of Ottawa /
 Research Ethics Board (REB).

Thank you for your interest conducting your research in our institution.



File Number: H05-13-10



Date (mm/dd/yyyy): 07/09/2013

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Dave	Holmes	Health Sciences / Nursing	Supervisor
Muhammad Arsyad	Subu	Health Sciences / Nursing	Student Researcher

File Number: H05-13-10

Type of Project: PhD Thesis

Title: Persistent Taboo: Understanding Mental Illness and Stigma amongst Indonesian Adults

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
07/09/2013	07/08/2014	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

File Number: H05-13-10

Date (mm/dd/yyyy): 07/09/2013



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

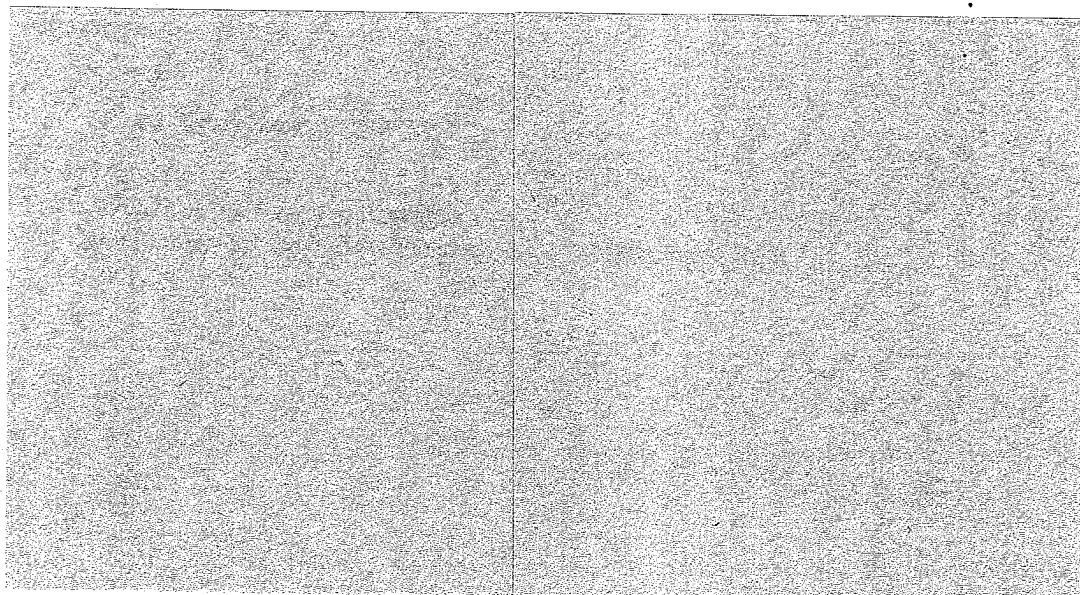
University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:
<http://www.research.uottawa.ca/ethics/forms.html>.

Please submit an annual status report to the Protocol Officer four weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:
<http://www.research.uottawa.ca/ethics/forms.html>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.





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Faculty of Health
Sciences

School of Nursing

APPENDIX C

Recruitment for a nursing study (Patients)

Hello,

My name is Muhammad Arsyad Subu and I am a PhD candidate in the School of Nursing at the University of Ottawa. Professor Dave Holmes is my thesis supervisor for my doctoral research titled ***Persistent Taboo: Understanding Mental Illness and Stigma amongst Indonesian Adults***. The objectives of this research are to understand the link between stigma and mental illness and to examine influences of stigma on access to mental health services amongst mentally ill adults in Indonesia. In addition, this research also wants to explore how mentally ill adult Indonesians perceive mental illness and how they respond to stigmatization in their daily lives.

If you volunteer as a participant in this study, you will be interviewed, once, by me, for a maximum of 1 hour.

This study has received ethical clearance from the Office of Ethics and Integrity at the University of Ottawa (Canada). However, the final decision about participation is yours. Participation is entirely voluntary. If you choose not to participate or to withdraw from the study, this will not affect your treatment, the quality of care you receive, or your relationship with healthcare providers.

If you are interested in participating, please contact me by email or phone. Participants will be accepted into the study on a first come / first served basis.

Thank you.

Muhammad Arsyad Subu, RN, PhD (cand)
School of Nursing
University of Ottawa
[REDACTED]
[REDACTED]

Professor Dave Holmes
Director
School of Nursing
University of Ottawa
[REDACTED]
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Sciences

School of Nursing

Rekrutmen untuk Penelitian Keperawatan (pasien)

Halo,

Nama saya Muhammad Arsyad Subu dan saya adalah seorang kandidat PhD di School of Nursing di University of Ottawa. Profesor Dave Holmes adalah dosen pembimbing tesis saya untuk penelitian doktoral saya yang berjudul ***Tabu Persisten: Memahami Penyakit Jiwa dan Stigma diantara Dewasa Indonesia melalui Grounded Theory***. Tujuan dari penelitian ini adalah untuk memahami hubungan antara stigma dan penyakit gangguan jiwa dan untuk menguji pengaruh stigma pada akses ke pelayanan kesehatan diantara orang dewasa dengan penyakit jiwa di Indonesia. Selain itu, penelitian ini juga ingin mengeksplorasi bagaimana orang Indonesia dewasa dengan gangguan penyakit jiwa menganggap atau memandang penyakit atau gangguan jiwa dan bagaimana mereka menanggapi stigmatisasi dalam kehidupan mereka sehari-hari.

Jika anda dengan secara sukarela sebagai partisipan dalam penelitian ini, anda akan diwawancarai sekali, maksimum selama satu jam.

Penelitian ini telah mendapatkan ethical clearance dari Lembaga Ethics and Integrity at the University of Ottawa (Kanada). Namun demikian, keputusan terakhir tentang partisipasi tergantung pada anda sendiri. Partisipasi adalah sukarela tanpa paksaan. Jika anda memilih untuk tidak berpartisipasi atau menarik diri dari penelitian ini, hal tersebut tidak akan mempengaruhi pelayanan dan kualitas perawatan, atau hubungan anda dengan para penyedia tenaga kesehatan.

Jika anda berminat untuk berpartisipasi, silahkan menghubungi saya melalui email atau telpon. Partisipan akan diterima dalam penelitian ini berdasar pada prinsip pertama datang / pertama yang akan diterima.

Terima Kasih.

Muhammad Arsyad Subu, RN, PhD (cand)
School of Nursing
University of Ottawa

[Redacted contact information]

Professor Dave Holmes
Director
School of Nursing
University of Ottawa

[Redacted contact information]

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School of Nursing

Recruitment for a nursing study (Nurses)

Hello,

My name is Muhammad Arsyad Subu and I am a PhD candidate in the School of Nursing. Professor Dave Holmes is my thesis supervisor for my doctoral research entitled ***Persistent Taboo: Understanding Mental Illness and Stigma amongst Indonesian Adults***. The objectives of this research are to understand the link between stigma and mental illness and to examine influences of stigma on access to mental health services amongst mentally ill adults in Indonesia. In addition, this research will also explore how mentally ill adult Indonesians perceive mental illness and how they respond to stigmatization in their daily lives.

If you volunteer as a participant in this study, you will be interviewed, once, by me, for a maximum of 1 hour.

This study has received ethical clearance from the Office of Ethics and Integrity at the University of Ottawa (Canada). However, the final decision about participation is yours. Participation is entirely voluntary. If you choose not to participate or to withdraw from the study, this will not affect your employment at the hospital or your relationship with your employer.

If you are interested in participating, please contact me by email or phone. Participants will be accepted into the study on a first come / first served basis.

Thank you.

Muhammad Arsyad Subu, RN, PhD (cand)
School of Nursing
University of Ottawa

Professor Dave Holmes
Director
School of Nursing
University of Ottawa

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School of Nursing

Rekrutmen untuk Penelitian Keperawatan (perawat)

Halo,

Nama saya Muhammad Arsyad Subu dan saya adalah seorang kandidat PhD di School of Nursing di University of Ottawa. Profesor Dave Holmes adalah dosen pembimbing tesis saya untuk penelitian doctoral saya yang berjudul ***Tabu Persisten: Memahami Penyakit Jiwa dan Stigma diantara Dewasa Indonesia melalui Grounded Theory***. Tujuan dari penelitian ini adalah untuk memahami hubungan antara stigma dan penyakit gangguan jiwa dan untuk menguji pengaruh stigma pada akses ke pelayanan kesehatan diantara orang dewasa dengan penyakit jiwa di Indonesia. Selain itu, penelitian ini juga ingin mengeksplorasi bagaimana orang Indonesia dewasa dengan gangguan penyakit jiwa menganggap atau memandang penyakit atau gangguan jiwa dan bagaimana mereka menanggapi stigmatisasi dalam kehidupan mereka sehari-hari.

Jika anda dengan secara sukarela sebagai partisipan dalam penelitian ini, anda akan diwawancarai sekali, maksimum selama satu jam.

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Jika anda berminat untuk berpartisipasi, silahkan menghubungi saya melalui email atau telpon. Partisipan akan diterima dalam penelitian ini berdasar pada prinsip pertama datang / pertama yang akan diterima.

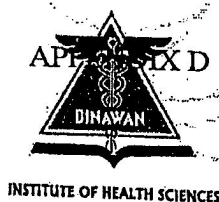
Terima Kasih.

Muhammad Arsyad Subu, RN, PhD(cand)
School of Nursing
University of Ottawa
[Redacted]
[Redacted]

Professor Dave Holmes
Director
School of Nursing
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LETTER OF VERIFICATION AS CERTIFIED TRANSLATOR

Jakarta, 18 June 2015

To Whom It May Concern

I am writing to verify that Mr. Muhammad Sahuri, M.A is currently employed, as head of Binawan Language Center (BLC) of Binawan Institute of Health Sciences Jakarta Indonesia. He is also a certified English translator. His responsibilities include translating documents (English to Indonesian or Indonesian to English) and managing all teaching of English subjects and courses at Binawan Institute of Health Sciences.



Dean

APPENDIX E
INTERVIEW GUIDE
(PATIENTS)

1. Could you please give a bit of a background about yourself?
2. Could you please explain to me why you are hospitalized here?
3. Could you please describe in your words your mental health concern?
4. How is it to live in Indonesia when you have a mental health issue?
5. Do you get support from your family? In what way?
6. On a daily basis, how do you cope (or adapt) with your mental health issue when outside the hospital?
7. What support do you have from nurses when hospitalized? How are you treated at the hospital? Is it better than outside? If so, in what way? If worse, in what way?
8. Have you ever been stigmatized by your family, friends or neighbors because you were different? How did you (or do you) feel about that? What was your response? Did it prevent you from consulting a mental health specialist?
9. In your opinion how does Indonesian society see or deal with mentally ill persons?

INTERVIEW GUIDE

(NURSES)

1. Could you please give a bit of a background about yourself?
2. Could you give me an idea of a standard day at work here at the hospital?
3. How do you define mental health/mental illness?
4. How is it to live in Indonesia when someone has a mental health problem? What support do mentally ill persons get from their family, friends, society at large?
5. What is a mentally ill person for you?
6. In your opinion, what are the needs of mentally ill persons? What is the best way to care for them?
7. What factors impede mentally ill persons' access to healthcare?
8. In your opinion how does Indonesian society see and deal with mentally ill persons?