

Persistent Taboo: Understanding Mental Illness and Stigma among Indonesian Adults through Grounded Theory

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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 as well as Paillé's 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.

Keywords — Stigma, mental illness, grounded theory, Indonesia

1. INTRODUCTION

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 [1]. The treatment of mental illnesses in Indonesia is not optimal [2]. 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 [3]. Over half of these psychiatrists work in the capital city of Jakarta [4]. The quality of hospital mental health services is also not ideal [5]. 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

[6]. Therefore, families tend to bring patients to traditional healers, religious leaders, or to those involved with other types of alternative treatments.

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 [7]. 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 [7]. 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 [7]. 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, [7] - 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), paranormal, 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 [7]. Even patients who do receive treatment at a psychiatric hospital may experience violence from hospital staff. Patients with a mental illness are often neglected, and hospital staffs do not treat them with dignity or respect and fail to protect them [8].

The aim of this paper is to present the results of a qualitative constructivist grounded theory research conducted in Indonesia that explored how mentally ill adults in Indonesia perceive mental illness and how they respond to stigmatization. This research sought to understand the relationships between stigmatization and mental illness and how they affect access to treatment. Equally important this research examined the role and practice of Indonesian nurses in a psychiatric setting and how they understand mental illness themselves.

2. METHODOLOGY

2.1. Design: Constructivist Grounded Theory

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. The constructivist grounded theory research approach was introduced by Kathy Charmaz. Charmaz's 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" [9]. 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" [9]. 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 [9].

2.2. Research Setting and Participants

This research was conducted at the major psychiatric institution of West Java province in Indonesia; it is one of the largest mental health hospitals in Indonesia. 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. A total of 30 participants (15 patients and 15 nurses) were recruited, which is more than enough to ensure data saturation [9].

2.3. Data Collection

During this qualitative research, thirty semi-structured interviews were conducted. All interviews were digitally audio-taped with each participant's permission. Along with interviews, mute evidence was part of data collection strategy. Mute evidence collected in this study was both hard copy and electronic, including nurse reports and logs, nurse performance ratings, meeting minutes, newsletters, and other materials such as the hospital's vision and mission statements.

2.4. Data Analysis

Paillé's (1994) method of grounded theory data analysis was used to organize and manage data [10]. It mirrors Charmaz's (2006) method of data analysis. Paillé's basic principles of data analysis include: *codification, categorization, linking categories, integration, conceptualization, and theorization*. Heath and Cowley (2004) propose three main stages in grounded theory data analysis: 'initial coding, intermediate phase, and final development' [11]. Based on these stages, Charmaz's (2006) constructive grounded theory starts with initial coding, focused coding (intermediate phase), and theoretical coding (final development) [9]. Similarly, 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) [10].

2.5 Ethical Considerations

Ethics approval for this project was obtained from the University of Ottawa Research Ethics Board (File number: H05-13-10) and follow the Tri-Council Policy Statement on ethical conduct for research involving humans. As such, we ensured that all participants in the study were able to give an informed consent to participate to the study and were informed that they could withdraw from the study at any time without any prejudice. Prior to each interview, participants were required to read and sign two copies of a consent form and were given one of the copies. Confidentiality and data protection were also ensured throughout the research process. 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. All confidential data and materials were kept locked at the University of Ottawa, in the University Research Chair in Forensic Nursing. Translators who participated in the study provided a statement that they would never divulge the materials that they have translated for the study.

3. RESULTS

Following rigorous qualitative data analysis, five categories mutually exclusive, but interrelated categories were identified: treatments, violence, fear, and constructing cursed citizens and stigmatization. Each of them will be presented/illustrated below.

3.1. Category 1: Treatments

Most of the patients who suffer from mental illness have been brought first to people who practice what is considered "alternative medicine". These alternative treatments are often the first choice of patients, families, and communities. A nurse reported:

Most [patients] went everywhere for alternative healers because they assume that they are possessed by demons... Family members think that [there is] no need to go to a psychiatric hospital. They go to chaplains first, to this place first, everywhere first... The majority go to the hospital as the last option. (N11, p.13).

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).

The lack of government attention, combined with other factors like stigma, have isolated patients with mental illness. 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).

3.2. Category 2: Violence

Patients' Violence

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).

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

I am the second of five brothers and sisters. I am the most difficult and am a burden for my family. Because of difficulties 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).

Physical violence against hospital staffs has become an endemic problem. Mental health nurses must routinely handle patients who are delusional, 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).

Violence Experienced by Patients

People with mental illness are more likely to be victims of violence. For instance the use of *Pasung* or *Seklusi*, which are lived by patients as forms of violence, 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 also reveal their experiences with *pasung*.

*The family and community members 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] took away my rights; all these are worse. Then, they tied me, like that sir. (P14, p.3-4).*

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

*Many times we admit patients who have been restrained... they 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).*

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).

But hospital staff often physically abuse patients themselves. Both restraint and *seklusi* 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. 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).

3.3. Category 3: Fear

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.

In Ngawi [a small county in East Java], I was [there] only three months; I 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).

Family members are afraid to deal with the instability or unpredictability of the patient, and believe that their relatives can be dangerous. 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).

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).

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

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).

3.4. Category 4: Constructing Cursed Citizens

Study indicates that patients are insulted, discredited, rejected, and devalued by people in society. 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. 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).

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).

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).

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 while, 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).

Due to 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.

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

3.5. Category 5: Stigmatization

According to participants, people in society still label the mentally ill person as “crazy” or “ex-crazy.” 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).

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).

Being labeled a “crazy nurse” because they work in a psychiatric hospital often leaves nurses feeling humiliated and insulted. 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” ohhhhh [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).

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

Like this, people outside assume that crazy people are very dirty. Terrible, 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).

Many people also have the stereotype that mental illness is an incurable and unalterable illness. In fact, there is an assumption that they are not able to function normally even after receiving medication, or they must take medication forever.

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).

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).

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).

Participants say that the social stigma attached to mental illness and the discrimination they experience have concrete effects. 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).

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).

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).

4. DISCUSSION

Study results show that patient participants were labeled ‘crazy’ or ‘ex-crazy’ persons the same way in it is often the case in Western countries [12]. Also, participants 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. People’s understanding of mental health treatment also rests on the belief that mental illness is incurable and unalterable [13]. They are also often depicted as inadequate and unlikeable, and as this study has found, sufferers can be considered social garbage or useless people [14]. The stereotype persists that people with mental illness are dangerous, meaning that they are unpredictable and threatening [15, 16, 17]. 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 [18]. Also, societal misunderstandings of mental disorders lead to the social exclusion of people with mental illness. The results of this study also indicate that there is a social distance or separation between people with mental illness and other people in their community [19]. Many of the patients were abandoned and ignored by families and community members. Patients then withdrew from their daily society life. Social avoidance from the patient's perspective is a protective factor where individuals with mental illness circumvent any social situation where others may discover their diagnosis [20]. Indonesian people with mental illness have experienced discrimination in their daily life, in the hospital, and in community settings. The effects of discrimination from stigma among patients with mental illness are well known [21, 22]. 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 [23], making marriage, childcare, work, and a normal social life much more difficult [24]. Negative views about the mentally ill are also widely expressed resulting in discrimination even in mental health care settings [18].

Study results show that 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 [18]. Indigenous healers for mentally ill treatments have a long history in Indonesia. For example, many patients who end up in clinics and hospitals have consulted one or several indigenous healers [25]. This study has demonstrated that many Indonesians who seek help from traditional healers for their treatment are also treated violently by them. When patients are admitted to hospital, they are sometimes enduring involuntary treatments, which include being forced to take medication, put in restraints or in seclusion, and being stripped.

Families and community members experience a burden of care with these patients and the mentally ill feel very clearly a lack of social acceptance. A lack of social support increases the sense of isolation often experienced by those with a mental illness [26]. People with strong social support networks recover more easily [27]. 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 with no benefit from long-term behavioural changes [28, 29].

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. Lack of knowledge and information about mental illness and its treatments are also barriers to accessing healthcare facilities in Indonesia. 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-income and middle-income countries [30]. 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 [31]. Stigma impedes patients from seeking treatment, can lead to them discontinuing treatment early [32], and can result in psychiatric re-hospitalization [33]. For patients themselves, admission to a psychiatric inpatient treatment centre can be experienced as disempowering and stigmatizing [34]. Svindseth, Hatling & Dahl (2007) found significant associations between humiliation and the patients' feeling that the admission was not right [35]. As this study has indicated, feelings of shame prevented many Indonesian patients and their families from seeking help; many were afraid of being labeled by others as mentally ill, and were ashamed to be put in a ward together with others with a mental illness. Mental health professionals themselves are a significant source of public stigma [36]; and people with a mental illness may feel unwelcome because of staff attitudes [26]. In addition, healthcare workers may lack skill in diagnosing mental illness and public health facilities may be limited in serving sufferers [6]. Patients may have more difficulty in obtaining a primary care physician or medical practitioners may diagnose and treat people with a mental illness differently [37]. The association of mental illness with violence or danger is a major cause of stigma for patients. The results indicate that patients are indeed violent, both in their family situations and in their communities. The link between violent behaviour and mental illness has been known for some time [38], and some studies have shown that mentally ill people engage in violence 2.5 times more than comparable demographic populations [39, 13].

Violence is not always directed against other people; suicide is often attempted by patients as the ultimate effort to solve their problems. Self-directed violence includes suicidal thoughts, attempted suicides or 'deliberate self-injury,' and completed suicides [40, 41, 42]. As this study has shown, patients with a mental illness can also be violent toward healthcare professionals. Both physical and verbal violent behaviors are common occurrences in hospitals and other mental health settings [43, 44]. Study results also indicate that 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 [45]. A Greek study found that mentally ill people report being victims of crime and discrimination more frequently than healthy controls [46]. In Taiwan, the abuse of patients with severe mental illness is higher than in the general population [47].

A close relationship exists between the violence experienced by the patients and the fear that they have. Feelings of fear can even contribute to violence and it makes mental illness far more severe by discouraging treatment and promoting social isolation [48]. 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. 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 [49]. 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 [50].

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 [51, 52]. Multiple studies have since suggested that stigma associated with mental illness creates a fear of being given this dangerous label [53]. Nurses working at the psychiatric hospital 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 [54, 55].

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 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. 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 [56]. According to Lazare & 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) [57]. 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. There is no doubt that the families are affected by the condition of their relatives. A concept called 'family stigma' – the negative impacts on family members of persons with mental illness [58]. 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. Family members are often blamed for their mentally ill relative, which may lead to feelings of shame themselves. They may believe that mental illness is caused by demons, or that it is contagious or hereditary.

5. CONCLUSION

As this study has shown, in Indonesia, 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. 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 in Indonesia and most likely will have a determinant impact on the quality of care mental health services utilization. In effect, the findings are especially 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. On the one hand, there is a need for nurses to facilitate interventions to counteract internalized and social stigma and, on the other hand, encourage nurses to practice reflexivity in determining their own misconceptions, perceptions, attitudes, prejudices, and discriminatory behaviors in the provision of care.

6. REFERENCES

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