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Before The Chains Are Broken: Considering Spaces and Accessibility of Mental Healthcare in Java

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BEFORE THE CHAINS ARE BROKEN:
CONSIDERING SPACES AND ACCESSIBILITY OF MENTAL HEALTHCARE IN JAVA

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SIT Study Abroad

Indonesia: Arts, Religion and Social Change

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Abstract

In 2010 the government of Indonesia initiated a “Free Pasung” movement to remove the physical chains of people who are in restraint because of their mental illness, or, patients in a state of *pasung*. In light of the program and national focus to “break the chains,” I became curious as to the systems of care in place for a patient once the chains are broken. The following paper is a product of three weeks of fieldwork divided between Jakarta and Yogyakarta, Java, Indonesia, aimed to address this inquiry. Through six semi-structured interviews with practicing psychiatrists, mental health specialists, and members of Parliament and the Ministry of Health in Jakarta, followed by two additional semi-structured discussions and two weeks of participant observation in government and private-operated systems of care in Yogyakarta, I hope to illustrate the state of mental healthcare in Java, and thereby complicate the notion of “breaking the chains” by analyzing the care that can be accessed once the chains are broken. Narratives from healthcare professionals, mental health specialists, patients and their families demonstrate the importance of contextualizing the practice of *pasung*. My findings reveal that beyond “breaking the chains” lies a need to consider the healthcare system in which the chains are applied.

Introduction

Sitting in a crowd of around thirty members of a village outside of Jakarta, Northwest Java, I watch as the presenter displays the next slide of his presentation. An image of two brains appear on the screen: the one on the left, shaded in mostly blue, is “normal,” while the one on the right, shaded in different colors to represent a chemical imbalance, is labeled as having schizophrenia. The presenter explains, “See, it is not because of some mystical thing or something like that, it is because of the brain.” Some community members sitting in the row in front of me nod their heads, while the woman to my right whispers something to the woman seated next to her.

I look at the poster adjacent to the screen, “*Safari Bebas Pasung: Together We Break the Chain.*” The presenter continues, “Schizophrenia is a disease. It is genetic and neurological.” Clicking to the next slide displaying the “need for drugs,” he describes that drugs can decrease the symptoms of schizophrenia and increase the patient’s social and life skills. After the symptoms lessen and skills develop, he explains, the patient can “reduce the amount of drugs from three to two to one pill per day, and sometimes even one pill per week.” The audience applauds.

The event is a product of a national “Free Pasung” movement that began in 2010 in Aceh, Indonesia, and subsequently spread to regions across the country. The aim of the movement, according to Dr. Rama Giavani, a practicing psychiatrist from Jakarta, is to release people with extreme mental illness who are in restraint, or, in the words of this presentation, to “break the chains” of people who are locked up because of their mental condition (R. Giavani, personal communication, November 8, 2015).

Translated from Bahasa Indonesia, *pasung* means to “punish a person,” and describes the physical restraint of a person by securing their legs, hands, or neck (Tyas, 2008). The practice of restraining people with mental conditions can be traced back to the 18th century when the French physician Philippe Pinel released patients from their chains whom were locked because of their mental illness. The act of restraint continues to be practiced globally within mental health hospitals, religious shrines, the homes of families, and other settings (Minas et al., 2008; Sa'ad, 2001).

More often functioning as the primary caregiver, the family is frequently found to be the source of applying *pasung*. Restraint can take the form of chaining, applying wooden stocks, or confining a patient to a room. It can also take place inside a family's house, directly behind a house, under a traditional stage house, or under a tree (Puteh et al., 2011). A 2011 study by Puteh, Marthoenis, and Minas in Aceh found the duration of *pasung* cases to range from a few days to 20 years, with a mean of 4.0 years. This length is consistent with the findings of Minas and Diatri on Samosir Island in Sumatra, in which *pasung* was applied from two to twenty-one years (2008). The decision to apply restraint is rooted in a variety of structural and subjective causes. Minas and Diatri found reasons to include families' fear of violence from the patient, fear that the patient would run away from home, and fear of suicide (2008). Puteh et al. found that families' decisions were rooted in economic barriers, including the cost of treatment, while also encompassing the financial burden of transportation to a healthcare facility (2011). Dr. Nova Yusuf, psychiatrist and initiator of the Mental Health Law, explained that as of 2013, 14.3% of the total population of Indonesia is in restraint, or, 56,000 cases (personal communication, November 9, 2015).

Returning to the Free Pasung event, a man from the back of the village hall steps forward to begin the next presentation, “How to Manage Relations with People in Pasung.” He explains, “People who are in pasung usually have severe mental illness. Eighty-nine percent are patients with schizophrenia.” In 2007, he continues, the prevalence of schizophrenia in Indonesia was 0.46%. He adds, “In that same year, zero members of this village went to a mental health hospital, and there were 3,124 cases of pasung in this district.”

“Now,” he explains, “Our mission is to Free Pasung by 2019. There needs to be a fast response team to release the patient and bring them to the hospital. We need to break the chains.”

Following the presentation, a team of psychiatrists, general physicians, medical students, and community leaders donned in matching green vests board five ambulances in preparation to release patients in five different villages. The sound of the sirens and flashing of lights sends crowds of students outside of their school and mothers outside of their homes to observe the spectacle. Women leave their shops, children cease to play, and groups of men pause their conversations, as ambulances take up the space of the roads and sirens silence ongoing activity. Dr. Nova looks back at me from the front of the car and smiles, “This is a human rights emergency.”

Research Motivation and Aims

Images of pasung, displaying chained frail hands and locked tired bodies, and documentaries, capturing the faces of patients whose voices are structurally silenced, led me to Indonesia. I spent the past academic semester staying close to the data as I contemplated what would drive a family to lock up a loved one and ruminated over the images of patients victimized in chains. After experiencing the Free Pasung movement first-hand, however, I began to question the treatment available for a patient who is released from pasung. I became curious as to what options for care are in place for patients of psychosis outside of the family's home, and to what extent these spaces of care are viable choices for a family. In other words: what are the options for a patient once the chains are broken? This inquiry and process of thought became the primary motivation and research question for my independent study project.

In what follows, I will describe my experiences in government and private-operated systems of care in Jakarta and Yogyakarta, Indonesia. I will begin by examining the space that a patient is initially brought to once released from pasung, the hospital. After discussing the challenges that a family can encounter when accessing the hospital, namely through the referral system and limited duration of care available for a patient, I will contrast the hospital to a privately-operated shelter built in response to these limitations. Next, I consider the feasibility for a patient of psychosis to access what can be described as the “lowest unit of services,” or the primary level of care, the *puskesmas* (S. Nanwani, personal communication, November 24, 2015). In analyzing primary care through a framework of the *desa*, or village, system, I will discuss two alternatives of care for those who cannot access services at the primary level. Finally, I will return to the space of family care to further contextualize why pasung is applied in the context of other options for care.

My hope is to complicate the notion of “breaking the chains” by questioning what services of care are in place, and can be accessed, once the chains are broken. By considering the challenges faced by families when attempting to navigate the healthcare system and evaluating the state of alternative systems of care in place, I hope to illustrate the context in which the chains are applied.

Narratives of the healthcare professionals, mental health specialists, patients and their families that were shared with me and the spaces of care in which I engaged with suggest that beyond “breaking the chains” lies a need to consider why the chains are applied. An analysis of options and accessibility of mental healthcare reveals that breaking the chains should come after evaluating the system in which the chains are placed.

Methods and Ethics

My fieldwork was divided between the distinct contexts of Jakarta and Yogyakarta, Java, Indonesia. My intention for both contexts lies in their recognized approach to mental healthcare. Jakarta is the context in which the 2014 Mental Health Law, initiated by my project advisor, Dr. Nova Riyanti Yusuf, was passed. This law was a concrete move towards improving the provision of mental healthcare throughout Indonesia, mandating efforts to strengthen mental health promotive, preventative, curative, and rehabilitative activity (Yusuf, 2014). I chose to observe how the policy-based understanding I acquired in Jakarta is implemented in Yogyakarta, a context that strives to, as explained by psychiatrist and researcher Professor Subandi, be a “prototype” for mental healthcare in Indonesia, having already taken the step of integrating mental health services at the primary care level (personal communication, November 24, 2015).

In Jakarta, I conducted six semi-structured interviews with Dr. Rama Giavani, Psychiatrist and Founder of “Indonesia Mentality Care,” Dr. Irmansyah, former Director of Mental Health, Psychiatrist and Professor of Bioethics at the University of Indonesia, Budi Anna Keliat, Professor of Community Mental Health Nursing at the University of Indonesia, Benny Prawira, Founder of the non-profit organization “Into the Light,” Nina Mardiana, Secretary of the privately-operated shelter “Yayasan Galuh,” and Dr. Eka Viora, Directorate General of Healthcare of the Ministry of Health. I also conducted a focus group discussion with Latifah Hasanah, Fatih Waluyo Wahid, Fitriana Yuliawati Lokollo, the Commission IX Expert Staffs of the Mental Health Law, and Arrista Trimaya and Woro Wulaningrum, the legal drafters of the Mental Health Law.

I grounded the policy-based understanding I acquired in Jakarta through my fieldwork in Yogyakarta, in which I engaged in participant observation for the remaining two weeks of the

independent study period. Dividing my time between a primary health center, or *puskesmas*, a mental health ward of a government hospital, and both a government-operated and privately-run shelter, I attempted to, as theorized by scholars Mike Crang and Ian Cook, participate in an “immersion of the researcher’s self into the everyday rhythms and routines of the community” while also recognizing the process as “a means of developing intersubjective understandings between the researcher and researched” (2007). In this way, I aimed to better understand my research inquiry of the spaces of care available and accessible to families once a patient is released from pasung. During this time I also conducted two semi-structured interviews outside of the spaces of participant observation; one of which was with an Islamic teacher, Pak Fadlan, in his center of Yogyakarta, and the other with Professor Subandi of the Faculty of Psychology of Universitas Gadjah Mada. The differing methodologies suited the distinct contexts, as in Jakarta I focused discussions on issues surrounding mental health theory and policy, from which I was then able to engage with on-the-ground through participant observation in Yogyakarta.

All participants of my study provided informed consent prior to all interviews and observation. For ethical consideration, I chose to leave the names and specific locations of the spaces of care unknown, as well as the names of the healthcare workers, families, and patients within those spaces. While I informed all I interacted with in the facilities I observed of my background and intentions, I chose to leave the identities of these spaces and the people within them out of my paper.

I am incredibly fortunate to have shadowed my project advisor, Dr. Nova Riyanti Yusuf, and my mentor in Yogyakarta, Dr. Sandeep Nanwani, both of whom provided access to the people and spaces I engaged with, and ensured comfort for the exchanges between myself and

each community. Their support allowed supported access for both the interviews and opportunity for participant observation, without which this fieldwork would not have been possible.

I. When There's a Cap on Care: The Limitations of the Hospital System and a Shelter's Response

After a patient is released from pasung, psychiatrists and participants of the “Free Pasung” movement escort the patient to the hospital. In this setting, a patient is able to receive care that is systematic and therapeutic. However, challenges arise when a family attempts to bring their patient to a hospital independently. Once the services are accessed, there exists a limited duration in which a patient can receive that provided care. These gaps lead families to seek, or resort to, other options for their patients.

In what follows, I will describe my observations and discussions within a mental health ward of a government-operated hospital to demonstrate the limitations of the hospital system. I follow with a description of a privately-run shelter that was created in response to these limitations. While providing a thorough sense of care, the hospital system encompasses gaps that make it challenging, if not impossible, for a family to access its services. The shelter attempts to fill in these limitations to the best of its ability, but, as I will describe, is not equipped to provide a care comparable to a government-funded facility.

The Hospital

The mental health ward of the government hospital sits on its own, separated from the expansive, connected hospital complex. Patients in this ward are made distinct from the rest of the patients as well, distinguished by their light purple uniforms. Intended to make them easily identifiable in the instance of potential attempts to, in the words of the ward's nurse, “run away,” the uniforms mark the space as different from the hospital's other departments. Ten rooms enclosed with vertical steel bars house the patients. Nurses sit in an adjacent station filled with surveillance cameras positioned in the patients' rooms. The offices of physicians and

psychiatrists lie above on the second floor, and families of patients are allowed to sit in the waiting area outside of the building.

The door between the inside of the ward and the outside surroundings remains open, as patients roam within the building, while occasionally choosing to sit outside on one of the chairs in front of the ward. The air from the outside travels in and out as family members occasionally walk inside to visit a family member or sit on a chair outside, waiting to bring a patient back to their home. One patient expressed that she liked the ward more than her village, while another patient described that the ward “is like a house” and how he enjoys “storytelling” with the nurse.

Treatment in the ward is delivered depending upon the severity of the illness. A nurse of the hospital for the past 32-years explains that patients in “crisis,” or, dangerous to themselves or to the people around them, are left to “enjoy the restraint.” These patients do not engage in any activity, but instead are physically restrained through ties or chemically restrained through sedatives in an effort to stabilize the patient. If illness is acute, or showing extreme symptoms without posing a threat to themselves or others, the nurse works to stabilize the patient by modeling activity, such as showing the patient how to eat or sit. The nurse leans in towards me to explain, “You can see a person laughing or getting angry because the voice is telling them to. I tell the patient to ignore the voice, that ‘It’s okay, what you’re listening to is just a hallucination.’” Nurses also encourage patients to actively resist the voices by telling the voice to “Get out of me.” In addition to medication, patients participate in occupational therapy and group therapy by making crafts, socializing with others, and practicing aerobics. The nurse describes these different levels of care by drawing a multi-tier triangle on the back of his log before looking up to see if I had any questions (personal communication, November 18, 2015).

The nurse's description encompasses the standardized system of care practiced in the hospital setting. Using terms such as "service" and "delivery," the nurse maps out the care given in this context onto a diagram in which experiences of illness are separated by tiers, dividing illness through categorization of symptoms. This standardization, however, allows for care that is systematic. Patients here engage in activities throughout their days, from aerobic exercises in the morning to group and occupational therapies scheduled in the afternoons and evenings. While the standardization of care is also embodied in the uniforms and enclosed rooms, there is a palpable sense of livelihood throughout the ward. Patients engage with one another and the nurses, sometimes sitting with their families outside. Patients are mobile, moving in and out of the open door. This sense of livelihood is evident in the shared experiences of the individuals I spoke with, one commenting that they preferred the ward to their home village, while another comparing the facility to "a house."

The hospital is where psychiatrists want patients who are released from pasung to be treated. It is the context in which patients of the "Free Pasung" movement are accompanied to and the location that the five ambulances traveled to that afternoon. Understanding, then, the limitations of the hospital is critical to understanding why families may choose, or resort to, alternative means of care.

For families of patients with psychosis, accessing a mental health hospital can be a challenge on its own. Dr. Irmansyah, a psychiatrist of a government hospital outside of Jakarta, explains "In general for most of the patients brought to the hospital, they are receiving the health service after they have had symptoms for many years, so usually after the symptoms are getting worse or agitated then they bring them to the health service. So between the first symptom until they reach the health service, it could be years." While this delayed first contact can be rooted in

what Dr. Iramnsyah terms “unawareness” of mental health, he also identifies the challenge of traveling to a mental health hospital itself. He explains, “The mental hospital is rare in Indonesia. It’s located in the cities, so it’s always a problem for people in rural areas, or other areas far from the cities, to access mental hospitals” (personal communication, November 11, 2015). Even if a hospital setting can be reached by transport, problems can arise in accessing services of care. In a focus group discussion I conducted in Jakarta with the legislators and legal drafters of the Mental Health Law, a legislator explained the difficulties of the referral system for a patient in pasung. She comments, “If you’re in pasung, there’s still confusion, and you usually get rejected. There are no regulations or guidelines for pasung. There is no such thing as a referral from pasung.” She continues by speaking about her own experiences in releasing patients of pasung: “You try to bring the case that you find in the field to the hospital because puskesmas are not ready to accept such patients. But the hospital cannot take them under BPJS¹ coverage because there is no such thing as referral from pasung” (personal communication, November 9, 2015). For a family actively wanting to provide their patient with hospital care, both physically accessing the facility by transportation as well as accessing the services through referrals and healthcare insurance can act as barriers to attaining care.

Once a patient accesses in-patient care, there is a limit to how long they can obtain that care. Professor Budi Anna Keliat, a professor of Community Health Nursing at the University of Indonesia, explains: “A patient can now stay in the hospital for 13 to 23 days. Patients used to be able to stay for years. Because if not, then the quality of care is very low” (personal communication, November 11, 2015). While Professor Budi describes the limitation of stay through limitations of care quality, the nurse of the ward I am visiting speaks about the cap in

¹ BPJS is the name of the national health insurance scheme.

terms of economic limitations. The maximum duration of stay in this hospital is thirty days, of which he explains, “A hospital, big or small, is still a business. If they keep a patient for too long, they can go bankrupt” (pc, November 18, 2015).

After a patient is discharged from the hospital, healthcare providers try to reintegrate patients into the home setting by empowering families to provide a routine of care consistent with that of the hospital. Professor Budi explains, “We do roleplay, we motivate them, show them how to take care of the patient and empower the family to take care of the patient.” After a pause, she admits, “But not all families do that” (personal communication, November 11, 2015).

At times, a patient’s family cannot be contacted after the patient is ready for discharge. Dr. Iramnsyah explains, “If the doctor decides that the patient is getting better, it is not easy to just let the patient out. Sometimes the family never shows up and even contact with the family is a problem. They only have the phone of a relative or the phone of a neighbor. It is not easy to contact them.” For families who cannot be contacted, hospitals have a system known as “dropping,” in which healthcare providers attempt to locate the patient’s address and “drop the patient” to the location. In the hospital in which Dr. Iramnsyah practices, this process happens to 10-20% of patients admitted with psychosis (pc, November 11, 2015). When discussing the experience of dropping with the nurse, he explains that the process usually occurs with families who are burnt out, or, those who have navigated the healthcare system multiple times. He explains, “For the first episode of psychosis, the family is often very caring. By the fourth or fifth episode, it’s as if the patient is thrown.” The nurse is quick to clarify that at that point he does not feel the responsibility lies on the family, but rather, on the state. “Families become saturated. If the family has completely lost options, it’s the state’s responsibility.” The process of dropping is

challenging for both the patient and the healthcare provider. The nurse concludes, “It’s the hardest issue” (pc, November 18, 2015).

The process of dropping encompasses the exhaustion and burnout that lead families to seek options of care outside of the hospital system. This concept of the effort, energy, and empathy demanded of a family with a patient of psychosis is captured in the framework of “caregiver burden.” Mental health researcher Sally Wai-chi Chan writes, “As caregivers struggle to balance work, family, and caregiving, their own physical and emotional health is often ignored. In combination with the lack of personal, financial, and emotional resources, many caregivers often experience tremendous stress, depression, and/or anxiety” (2011). When taken in this framework, compounded with the structural challenge of access to both a hospital and the services within the facility, a family’s desire for long-term rehabilitation can be better understood. Beyond the challenges of reaching the mental health hospital or accessing services within the hospital lies the cap on care that a patient can be provided with. For a family experiencing “caregiver burden,” the limited duration of stay in the hospital system is enough to lead them to alternative forms of care.

The Shelter

Dr. Nova and I have difficulty finding the shelter, situated in a remote area in the outskirts of Jakarta. After a series of winding roads and conversations with shopkeepers and taxi drivers for directions along the way, we approach an area of dirt and construction. Dr. Nova comments, “Oh they’re being renovated.”

In the center of the compound sits what appears to be a two-story cage: a large square structure enclosed with metal bars. The first level consists of four 15 x 15 foot areas, divided

separately by their own sets of bars. Each area is bare, without mats or beds, and holds 20-30 patients. There appears to be enough space to sit, but not to lie down comfortably. As we pile out of the car, faces emerge through the gaps of the bars. Many patients are not fully dressed, some are fully naked. A healthcare worker hands plates of white rice between the metal bars, and one patient is handed a sweater. There is a sense of excitement when Dr. Nova and I approach the structure, as we begin to share about where we are from and how we want to see the shelter.

The shelter began in 1982 when the founder saw a person with a mental disorder being bullied on the streets. He took the person to his home, and slowly the house became a space open to people with a mental disorder who would otherwise be homeless. Since 2014, psychiatrists come weekly to the shelter. Treatment is provided through a variety of practices, including donated medicine, traditional herbal regimens, sedatives, and prayer, facilitated by Buddhist, Catholic, Christian, and Muslim priests who visit the shelter on a monthly basis. Patients engage in activities, such as making crafts and folding menus that will be used by a nearby restaurant. There is an isolation room separated from the steel-barred structure used for patients when they become agitated (Shelter secretary, personal communication, November 10, 2015).

While in the beginning the founders of the shelter worked to identify patients, now police and security bring selected people with psychosis found on the streets to the shelter. In an interview with the secretary of the shelter, she described the space as a “go-to” location for police and security forces. The space, however, is also actively sought out by families. Termed by the secretary as “the last-destination,” the shelter is where many families resort to after attempting to gain access to a hospital or having a patient discharged from a hospital. Unlike a hospital, in which patients must have health insurance coverage as a product of a proper referral, the secretary describes, “We will not reject them here.” Any patient who is brought here, whether

by police or a family, can stay. Beyond patients with psychosis, people of old age, with dementia, and children with autism also reside in the shelter. While the shelter has a policy that mandates families to visit their patient at a minimum of once per month, in reality, the secretary explains, the family will often move away to an area distant from the shelter. She describes, “In many cases this is the final goodbye” (pc, November 10, 2015).

Leaving the shelter, I feel the same knot in my chest as I did when I first saw images of patients in pasung or films of people with mental illness chained, months ago. This shelter is the subject of a documentary I had seen before coming to Indonesia and was the seed of much of my efforts to better understand mental healthcare. This time, however, my chest was not in pain because of the chains themselves, as it had been months prior, but instead because of the system that leads to the chains. What the documentary does not capture are the efforts and exhaustion of the caregivers of the shelter. The woman I interviewed works from early morning, when she serves the patients breakfast, to late evening, after most have gone to sleep. All of the caregivers manage three shifts each day. The woman resides next to the shelter, and can point to her home from where we are standing by the cage. She does not have adequate healthcare of her own. The documentary does not discuss how families try other systems of care and often come here when those efforts are exhausted. The shelter accepts patients without a required payment and is a space for long term rehabilitation; patients often remain here for 10-15 years. When they become stable, patients can become employed as kitchen or cleaning staff for the shelter and contribute to assisting new patients (Shelter Secretary, pc, November 10, 2015).

In addition to the “caregiver burden” that leads families to bring patients to long-term rehabilitative facilities like the shelter, exists the burden of the working staff. Not unlike families whose perceived options of care are exhausted to the extent that patients are dropped as the “final

goodbye,” my conversations with the shelter staff capture a similar sense of fatigue. Images of the shelter’s steel bars and bare rooms must be contextualized by the limitations of the hospital system and narratives of the staff.

As Dr. Nova is quoted as saying in an article about the shelter, “In a broken system, it is unfair to punish those that are trying to do good. Despite what we may think is correct, the reason that there are foundations that do pasung, is that the [mental health system] is broken” (Bhaskar, 2013). The faces that emerge through the bars of steel, and bodies that sit on the bare floor, must be contextualized as situated in a space where they will not be rejected by lack of health insurance, or given a cap to the amount of care they can receive. In this way, the shelter can be seen as an alternative form of care to fill in the gaps of the hospital system: gaps that are critical for the care of patients and their families.

II. Outside the *Desa*: Minimum Healthcare without Primary Healthcare

Primary healthcare is accessed through the *puskesmas*, or primary health clinics that provide basic services and are structured at the sub-district level across Indonesia. The *puskesmas* system is based on the *desa*, or village system. Health insurance can only be accepted from the *puskesmas* within a person's village, and moreover, the structure of the *puskesmas* and services within them, of which focus on care for the nuclear family, embody this concept of the village (S. Nanwani, personal communication, November 24, 2015).

What happens then, to patients of psychotic illness who have run away from their village as a symptom of their condition, or have been displaced as a product of shame? In what follows, I will analyze the *puskesmas* through the framework of the *desa* and discuss two spaces where patients who do not fit into the village framework are provided care. In discussing the barriers that prevent patients of psychosis and their families to access the *puskesmas*, I will consider how a minimum standard of care is interpreted and provided to those unable to obtain services at the primary level.

The Puskesmas

“From my experience in Indonesia,” Dr. Rama Giavani, a psychiatrist from Jakarta explains, “I still think people are not aware if they have a problem, if they have some disorder about mental health. They don't know where to go” (personal communication, November 8, 2015). The closest in proximity and, as Dr. Sandeep Nanwani describes, “the lowest unit of healthcare,” for families to go to is the *puskesmas*, or primary healthcare clinic. Regulated by the District Health Office, *puskesmas* are divided at the sub-district level and designed to provide

care for the population. In Indonesia, there are 10,000 puskesmas divided among 500 districts (S. Nanwani, pc, November 24, 2015).

Upon entering a puskesmas in the heart of Yogyakarta, the first question that Dr. Sandeep and I are asked is whether we have some form of identification. Dr. Sandeep is here to have a health form filled out by the physician. Because he is from Jakarta, Dr. Sandeep's health insurance does not cover this area and he pays the front desk an administrative fee to have the form filled out. The puskesmas is divided by the services it offers. One room in the building is for maternal and child health, the one adjacent to it is for dental care, the next is for TB, the following is for HIV, and another is for general health. Yogyakarta and Jakarta are the only provinces in Indonesia that have begun the process of including mental healthcare at the primary healthcare level. The last room of the clinic is dedicated to psychological services. Dr. Sandeep is told to take a number, or a square piece of cardboard that is color-coded and divided by these categories. After taking one for general health, we sit down and wait to be called.

The walls of the puskesmas are filled with different signs displaying their services. The sign in front of us displays a family of four, with two parents, a daughter and son, and lists steps towards HIV and STD prevention. The sign adjacent to it states that to access contraceptive and maternal health services, the BPJS, or health insurance card, is required. To the left is a schedule of weekly services with general, dental, and HIV/STD services offered Monday through Saturday, maternal and child services offered on Tuesday, and psychological services provided Monday, Wednesday, and Friday.

This puskesmas is unique to those commonly found throughout Indonesia, as Yogyakarta is one of the first districts that has begun to integrate mental health services at the primary level. As Dr. Sandeep explains, the central government ensures that every puskesmas sets a standard of

basic services through a system of minimal standards which dictate which services can be offered (pc, November 24, 2015). In its current state, the puskesmas system is, as explained by a legal drafter of the Mental Health Law, “not ready to accept patients with psychosis.” She continues, “Primary healthcare centers do not have guidelines or medication for these patients” (pc, November 9, 2015). Beyond medication, physicians in primary healthcare are not yet trained to treat disorders related to mental health. Dr. Eka, Directorate General of Healthcare of the Ministry of Health, explains, “In reality, most of the doctors in the primary healthcare don’t have confidence to treat patients with psychosis. If they find patients with psychosis they will refer them to the mental hospital. In this way, there is stigma from the healthcare provider themselves” (pc, November 9, 2015).

The Ministry of Health has created a national plan to replicate what is ongoing in Yogyakarta by including mental health services at the primary healthcare level. Dr. Eka explains, “Our priority in Ministry of Health is to strengthen primary healthcare to provide mental health services to increase the accessibility and the quality of services.” The plan for this integration is based on the concept of family. Already existing community health volunteers in each village will be trained to educate families about mental health. Dr. Eka explains, “The volunteers are neighbors, coming from the same community. In our culture, it is more family-oriented. There is the notion of extended family. All neighbors are considered to be family” (pc, November 9, 2015).

The environment of the puskesmas and words from the Ministry of Health reveal the role of the *desa* and nuclear family in primary health and upcoming mental health care. The posters, including those dedicated to HIV/STD prevention, display images of a father, mother, and their two children, a son and daughter. The available services themselves, which range from general to

maternal/child to dental health can be seen as reflective of the life-cycle of family medicine. Efforts to expand mental health care are also dependent upon the concept of the family, with plans for community health workers based on the “notion of extended family” and integrated into the village system.

When I spoke to Dr. Sandeep about this observation, he explained that this is reflective of not only care within health facilities themselves, but also within the system of healthcare insurance. He explains, “Basically the whole healthcare system is based on the desa system. To access healthcare, you need to belong to a household in a village” (pc, November 24, 2015). This was evident in our visit to the puskesmas, in which the first communication we had with the staff was a request for a form of identification, and the need for Dr. Sandeep to pay for the service because we were at a clinic outside of his place of origin in Jakarta. Scholar Martin Ramstedt situates this concept of the desa-system in the framework of David Delaney’s “nomosphere.” Delaney writes: “The idea of a nomosphere may be particularly apt to the extent that rights are understood as the gossamer filaments that connect our embodied lives to specific fragments of the world – to places, especially to ‘home’ and to ‘homeland.’” Ramstedt contextualizes this in the framework of the desa-system by explaining:

Arguing against a narrow reading of “law” that merely equates the term with “state law,” Delaney’s much broader concept of “the nomic” sets all “world-constituting rules,” like rules of politeness and etiquette, customary law and ethics, religious and kinship norms, professional procedures, and, we might add, feeling rules on an equal footing with the legal. “Feeling rules,” according to Arlie R. Hochschild who coined the concept, are a form of social control that is less explicit than other normative orders. Feeling rules are inherent in etiquette, tact and ethics but also worship and ritual. They require cognitive bodily emotion work by consciously altering, masking, reinterpreting or physically releasing what our social environment deems to be inappropriate feelings (2014).

Ramstedt explains the importance of one’s “home” and “homeland” to not only accessing rights such as healthcare, but in creating an unspoken system of what is appropriate in terms of norms,

be it in the framework of, as he describes, politeness and etiquette, laws and ethics, religious and kinship, professional, and even, in his words, what is constructed to be “appropriate feelings” (2014).

It is critical, then, to consider the implications of basing mental healthcare and access to care in the framework of the desa. Dr. Sandeep explains that people with psychosis who “have run away because they have psychotic illness” or “are displaced outside of their home because their families have completely given up” are no longer a part of their village. He describes, “People outside of the desa system are people outside of the household” (pc, November 24, 2015). Reflecting upon my visit to the puskesmas, I wonder how patients who have run away from their village as a symptom of psychotic illness would be able to access even the primary level of care. Furthermore, how does a family-based mental health system account for, as Benny Prawira, founder of the mental health NGO “Into the Light” explains, families who “feel shame to have a family member that acts that way”? What happens to patients who are displaced as a product of shame? In the context of the nomosphere, what happens to a person with psychosis whose behavior, etiquette, and feelings do not fit with the village’s constructed “norms”? This is particularly relevant when considering the context of Java, in which, as anthropologist Thomas Stodulka describes, “refined speech, restraint and propriety, and deference and respect” are “social norms of interacting in public” (2015). How does a patient of psychosis fit into this context? What happens to the patient who has either run away or has been shamed away from their village when village membership is central to accessing care, even at the primary level?

Camp

“Patients of psychosis who are on the streets,” Dr. Sandeep explains, “are brought to ‘camp,’ a social shelter operated by the Ministry of Social Affairs. We can go there tomorrow if you’d like.”

Behind the security check-point and office buildings sit two large structures enclosed with metal bars. The spaces locked are bare. Around sixty women sit and stand. Approximately forty men sit in the ward adjacent to them. When I ask the security guard why they are here, he points to his head and explains “They are sick.” When I ask sick with what, he responds with “gila,” or “crazy.” “They are crazy,” he answers. I nod. “How is care provided here?” I ask. The guard explains that they receive medicine two to three times a day so that “they can sleep” and be relaxed. Dr. Sandeep confirms that these are sedatives. In response to what must have been my noticeably concerned expression, the guard reassures me that they are taken care of here. “Look they’re fat,” he says. “They just sleep and eat” (pc, November 17, 2015).

I observe as five empty cups are passed among the women to drink water from. The cups are always shared among the patients, the guard explains. There sits a bathing area behind the caged structure, visible to all members of the camp. A guard holds a topless woman by the head as two other women quickly stand up to attempt to dress her. The head of the shelter tells us that “Camp is just a temporary place” (pc, November 17, 2015).

Next we walk into the separated section of camp for people who are described as “non-psychotic.” Unlike the previous area, this space has rooms filled with *waria*,² groups of young boys in tattoos, and thin, elderly people. The guard explains that they participate in activities throughout the day. The rooms have simple beds and mats.

² A term in Bahasa Indonesia to describe transwomen.

The final visit to camp occurs three days later. This time we speak with a nurse to learn more about the care provided here. We learn that there are 193 people in camp: 93 are described as “non-psychotic,” with the remaining 100 as “psychotic.” When a person is first brought to camp, they remain in a ward for twenty-four hours until the psychologist can determine their placement. This ward contains everyone: men, women, waria, and patients with and without a mental condition. Two doctors and two psychologists work at the camp on a weekly-basis. There are two nurses here each day responsible for the 193 in-camp residents. Their shifts begin at six am and conclude at three pm, after which the patients are left with the camp’s guards (Camp Nurse, pc, November 18, 2015).

The nurse offers to show us the room for patients of psychosis who have “serious illness,” or those who are “bed-ridden and cannot self-care.” Nine patients lie on wooden surfaces arranged inside the room, while two remain outside. When we walk in, the patients remain there lying. No one looks up. Flies and mosquitoes crowd the patients, gathered on their food and bodies. The nurse explains, “This person is post-stroke and cannot walk; this one was hit by a car; that one was hit by a motorbike.” While some patients have been here for a few weeks, one has stayed for a year and another a year and a half. Most have been in here for several months (Camp Nurse, pc, November 18, 2015).

The nurse wishes that patients could be sent to the public mental health hospital, about an hour away. The conditions here are a product of financial barriers, he explains. While in most cases the police bring individuals to the camp, including those with and without a mental condition, in some cases patients are referred here from the hospital or puskesmas. The nurse explains, “We have one patient with TB who was homeless, and another with a coma from an

accident.” The families could not be contacted, so the respective health facilities referred the patients here (pc, November 18, 2015).

Returning to my previous inquiry of the process of care for patients who do not belong to the desa-system, it becomes clear that people housed in camp encompass this demographic. People with psychotic illness who are found on the streets, either because they have run away as a product of their condition, or because they have been displaced as a product of shame, fill the enclosed structures of camp. The social shelter, however, is not just for people with a mental condition. I observe waria, young boys with tattoos, people with torn dress and unkempt hair, young girls, and elderly people mixed together behind the bars of camp. Their placement here results from being found by the police, Dr. Sandeep explains to me. They are found on the streets, either begging or engaging in other activity that leads authorities to bring them here: a social shelter operated by the Ministry of Social Affairs (S. Nanwani, pc, November 24, 2015).

When contextualized in the framework of the “nomosphere,” it becomes evident that the placement of individuals in this camp is perhaps a product of not merely a diagnosis, but also a socialized construction. In “Dealing with Schizophrenia in Central Java,” researchers Manfred Zaumseil and Hella Lessmann describe perceptions of people with schizophrenia as “deviant” from what can be considered the socially constructed “norm” within the context of Java. They write, “The main indicator for identifying people who are not normal (‘orang kurang waras’) or mad people (‘orang gila’) in our sample was deviant social behavior.” Concluding, the authors note: “It appears, then, that special forms of behavior which violate social rules and failure to fulfill one’s social role are the main everyday criteria of mental illness” (2007). The same framework of “deviance” has been used to describe people without a mental condition, yet whom

are found on the streets of the same context. Describing the “street community” in Yogyakarta, anthropologist Thomas Stodulka writes:

The young men’s collective tekyan ideology was articulated through a masculine display of tattoos, piercings, extravagant haircuts or long hair, public alcohol consumption, and ‘shameless’ swearing and shouting. To further distance themselves from ‘normal Javanese’ youths and adults, they had developed their own Bahasa senang – the ‘happy language’ (2015).

Stodulka situates street activities including alcohol consumption and “swearing contests” in the framework of “‘deviant’ cultural practices,” describing them as “particularly uncultivated (kasar), not-yet-Javanese (durung Jawa), even not-yet-human (durung wang) behavior” within the Javanese “cultural context.” The framework of deviance reveals a social construction of both patients of psychosis and people like those found in camp, whether waria, the elderly, or “street youth,” as outside of what can be considered, as Stodulka writes, ‘normal Javanese’ (2015).

The term “deviance” lends itself to the concept of marginalization, or, as scholars Gurung and Kollmair theorize, a social condition encompassing “lacking opportunities, resources, and skills” that “arise from ascribed markers related to ethnicity, gender, sexuality, social rank, political attitude or religion” (2014). In an interview with Dr. Sandeep, he elaborated on the marginalized character of those put in camp, with:

People outside of the desa system are people outside of the household: people who live on their own, or people on illegal land, or patients with psychosis, whose families have completely given up because of lack of care, or people who have run away from their family because they have psychotic illness, or even other people who don’t want to come out to their family because of their sexuality or because they are prostitutes or street-based workers. All of these people outside of the household system are on the margins. They don’t have access to healthcare at all because it is based on a desa-system, which they are not a part of (pc, November 24, 2015).

People who exist socially on the margins are then placed in the spatially marginalized context of camp. Authors Stodulka and Röttger-Rössler define a marginal area as “an area lying at the edge

of a system,” which has “geographically obstructed accessibility to economic centers, lacking infrastructure, or an exclusion from technological advancements” (2014). Situated on the physical margins of Yogyakarta and locked behind bars that prevent access to that of a “real or imagined hegemonic mainstream society,” the experience of camp can be thought of as encompassing both social and spatial marginality (Stodulka & Röttger-Rössler, 2014). As the guard of the shelter described the camp as a “temporary” space, so too does spatial marginality encompass conditions that are “not considered to be fixed states, but possess an innate potential for social change” (Stodulka & Röttger-Rössler, 2014).

The care provided in the context of the shelter can be considered different than the systematic form provided in the hospital, or the integrated services of a puskesmas, and instead as a temporary provision of a minimal standard of care. Similar to what medical anthropologist Peter Redfield writes of the context of a refugee camp, the camp maintains a state of “minimal existence” for patients by providing basic services that administer “survival within wider circumstances that do not favor it” (2005). The camp defends a minimal state of existence for patients of psychosis, without offering the facilities of therapy and structured activity, or those of an elaborated lifestyle. The nature of the space as temporary and its inaccessibility of what can be had by “mainstream society” pushes patients of camp into a compounded marginality, both socially as well as spatially. The camp, then, can be considered the space in which the state provides a minimum standard of healthcare for those who are not afforded access to primary healthcare.

The HIV Shelter

Twenty minutes away from camp sits another set of rooms filled with a community of waria, youth with unkempt hair and worn clothes, and patients with psychotic illness. The building sits in a residential area of Yogyakarta. A television blares with music videos in the center of the room, adjacent to which hangs a daily schedule of the week's events. With open windows and an open door, people come in and out of the building on all of my afternoons here.

In the center lies a seating area where both the lively waria and patients of psychosis sit, together, sharing coffee and, what seems to be commonly, conversation and laughter. I watch as they pass around a photo album of the waria of the shelter donning elaborate dresses and makeup. A patient laughs as one woman jokes that she will find the patient an attractive boyfriend from Bangladesh. One waria puts down her cigarette to admire the patient's medicine container, decorated with colored flowers.

The care given in this space is facilitated by Mommy, an identified waria who founded and maintains the center. In what started as an NGO for the waria community, the space has become a rehabilitative shelter for patients of psychosis or people living with HIV, while also maintaining its founding purpose of bringing the waria community together.

Returning again to a framework of deviance and marginalization, the shelter is run by a community that perhaps faces a stigma shared with those unable to access services of the puskesmas and those referred to camp. Scholars Stodulka and Röttger-Rössler elaborate on Link and Phelan's theory of stigma as "when particular 'others' are distinguished and labeled 'different,' their 'difference' is associated with negative attributes, 'they' are separated from 'us,' and finally ascribed a status loss that results in 'their' discrimination" (2014). This stigma can pervade into the referral system that brings certain groups to social shelters and contexts like camp. Considering experiences of mental health specifically, anthropologist Neely Myers

discusses stigmatization in the concept of “social defeat,” in which she describes the “instinctive rejection” of people with mental illness by “‘normal’ outsiders” (2015). Perhaps beyond formal diagnosis, the markers that identify some people on the streets as “different” than others is a product of such an “instinctive rejection” or “ascribed” loss of status.

When I sit down to interview Mommy, she struggles to speak with me about her interactions with the patients and the way in which care is provided here because, she explains, “it depends on the person and the relationship with the person.” Laughing, she says that she considers herself the mom and this as everyone’s house. Regarding counseling, she explains how the people here “just want someone to hear and understand what they feel without judgement.” She continues by explaining that she is not a “counselor,” and that she and the people of the shelter discuss “real things” and “real problems.” She concludes, “Here it is more than counseling. It is a relationship and care” (personal communication, November 15, 2015).

In learning more about the day-to-day structure of the shelter, it becomes clear that what can be considered therapeutic activity is practiced differently here than that offered in a mental health hospital or formal healthcare system. Rather than engage in structured activity, like the occupational or group therapy offered in the hospital I visited, the waria and patients here go together on outings to the mall or for a walk on Malioboro Street. In this way, the patients are able to, as Dr. Sandeep often articulates, “fight,” against instances of stigma and encounters of “social defeat.” Dr. Sandeep and I speak with one patient who at first did not want to join on these trips, as she felt that “people outside would look at how she is walking,” but after encouragement from the shelter community, she joins them every week (personal communication, November 15, 2015). Mommy explains to me that she also facilitates this care by providing examples of former patients to “give imagination” to those currently in the shelter.

Dr. Sandeep describes one patient who stays in the shelter to help facilitate care to other patients. He states that “her therapy will not continue if she goes home,” explaining how remaining in the shelter is “rehabilitative” for her, as it enables her to work and participate in daily activity within a community (pc, November 15, 2015).

Considering that the communities of individuals within the shelter are from similar communities of those in camp, and that people now in the shelter were previously placed in camp, it is critical to examine the differences in how care is facilitated in both contexts. While both patients of camp and patients of the shelter can be considered, as Dr. Sandeep describes, “people outside of the desa system,” while in shelter, patients can acknowledge and communicate shared experiences. Returning to Stodulka and Röttger-Rössler’s work, they explain, “A stigma never exclusively effects individuals, but stigma-related emotions dissolve into the social network of one’s family and community.” They continue, “Stigma is contagious in terms of the shared emotions between the stigmatized person, her or his partners, friends, family, and community” (2014). This concept of stigma as not an individual, but collective, experience becomes relevant when considering the shared instances of stigma experienced by the shelter community. Unlike the space created behind the metal bars of camp, the house-like environment is conducive for dialogue among distinct groups with overlapping experiences. The dynamic also encompasses the concept of “group emotions,” or “emotions that individuals experience as a result of identifying themselves with their fellow group members” (Stodulka and Röttger-Rössler, 2014). Perhaps shared experiences of marginalization and stigmatization weaves a common “emotional climate” among members of the shelter (Stodulka and Röttger-Rössler, 2014).

Beyond the physical environment, the shelter facilitates this type of community through the interpretation and practice of care. When Mommy speaks about her experiences, she has difficulty answering questions regarding “care” because she does not want to “generalize.” She emphasizes how dependent care is upon the individual. Moreover, when speaking about the shelter she uses kinship terms such as “mom,” “family,” and “house” (pc, November 15, 2015). Rather than a healthcare facility, care is interpreted and given in the framework of community.

While the shelter catalyzes a sense of community and facilitates an environment of dignity, it is crucial to recognize the limitations that allow the shelter to function as it does. Members of the shelter, explains Mommy, find the community at “random,” either through a referral from a friend, or in some cases, *Google* (pc, November 15, 2015). There lies a limited number of beds. And while each person shares a space with just one other member, there are only five rooms. Still, the shelter enables patients to receive a sense of community in combination with medicine from the formal healthcare system that reimagines what can constitute care. Dr. Sandeep describes that while it has its limitations, the shelter has been critical to “giving him hope” for mental healthcare (pc, November 24, 2015).

III. Chains as Care: Considering the Family when Options are Exhausted

After attempting to navigate the healthcare system, families can feel that their options and efforts have been exhausted. This leads families to attempt to provide care within the context of their home. Two common practices for care in the home are those of spiritual support, and, what can be considered a form of care when other options are exhausted: *pasung*. In what follows, I will examine how families provide care at the home-level when they have exceeded their capacity to navigate the healthcare system.

An Islamic Teacher

If a family does not want, or does not find, a shelter and has experienced the process of re-navigating the healthcare system, the family may, as Dr. Iramnysah describes, “self-medicate” (pc, November 11, 2015). A common source of family care is through use of spiritual healers.

When I sit down with an *ustadz*, or Islamic teacher, on the outskirts of Yogyakarta, he nods conformingly when I question whether he ever receives patients who see things or hear voices that are not really there. “Yes,” he responds, explaining that he receives these sorts of patients frequently. The most recent case was a young woman who for the past fifteen days saw a vision in her house and could not sleep from 10 pm to 4 am each day. To treat her, the teacher explains, he recites verses from the Qur’an in this room for an hour. For patients who show these specific symptoms, he recites verses intended to heal, verses to guard people, and finally, verses that offer protection from evil (pc, November 19, 2015).

The teacher shows me the form that he uses for each person who visits him. The left side of the paper lists the patient’s name with their symptoms and the right side lists the treatment in accordance with specific verses. The treatment type depends on the severity of the illness. If a

patient's symptoms are severe – for example, they are unable to eat or sleep – they must visit the teacher every day. With mild symptoms, he explains, such as experiencing nightmares or waking up in the middle of the night, the patient can visit once a week. Each visit costs 125,000 rupiah, regardless of the treatment (pc, November 19, 2015).

He notes that the family is always involved in the treatment process. For the young woman, her family helped bathe her in holy water in addition to the verses to complete her healing. For all patients, the family needs to practice the recommended prayer together with the patient. When asked the most difficult illness to help treat, he responds it is when a patient shows these symptoms of imagining sensations that do not exist as, he explains, “Patients are confused and don't know him or herself anymore” (pc, November 19, 2015).

The teacher's care is systematic. He lists the symptoms of the patient on a form and after considering verses, recommends what he believes to be most fitting for the patient's experience. Yet, he also considers just that: the patient's experience. When discussing a person who perceives phenomena that is not there, he does not describe it in terms of the patient having a disease, as found in the healthcare system, or being “crazy,” as in the social shelter, but rather explains the sensation in terms of the individual. He commented that “Patients are confused,” as they “don't know him or herself.” This description and the act of having the family recite verses, together, creates a remedy less prone to stigma, as it is contextualized into, what anthropologist Bryon Good terms, the specific “lifeworld.” In his ethnography about experiences with psychosis in Java, Good explains that common to both the Javanese lifeworld and the lifeworld of patients with psychosis is the phenomenon of unseen spirits. He explains, “There is less of a disjuncture between the everyday world and that of those who are psychotic than some societies have” (2004). Thus, seeking care from a healer provides a form of treatment that does not label the

experience as unusual, or out of the constructed norms of this specific context. It is also an accessible option for families, as they need not navigate the referral system or have health insurance as a concern. Each treatment has a flat rate.

Before coming to Indonesia, much of the ethnography I studied revealed that it is common for families across Indonesia to understand psychosis as a religious phenomenon. In his ethnography on a patient named Yani, anthropologist Byron Good explains how rather than use the term “schizophrenia,” the patient describes her experience with concepts from Javanese Islam. Good writes, “Psychiatric conceptualizations of schizophrenia are almost absent from our conversations” (Good et al., 2004). This is consistent with Tyas’ ethnography in Aceh, a context in which the term “pungo” or ‘mad’ is used to describe behavior “caused by something beyond a human being’s sense or ability to control” and “pungo nahu” is termed to describe “a person’s madness due to over learning the reading of the Qur’an” (2008). Similarly, anthropologist Harald Broch found that the community of his study in central Sulawesi often sought care from *dukun*, or local Islamic healers, who used remedies including massage (*urut*), blowing (*siram*), offerings (*bao koni*) and herbal medicine to treat what can be considered symptoms of psychosis (2001).

The literature on this concept is consistent with the interviews I had with healthcare professionals in Jakarta. Dr. Rama Giavani explained, “I think if [families] know that it is a problem with disease they will bring them [to the psychiatrist]. The problem is they don’t know. They go to some *dukun*. They just pray” (pc, November 8, 2015). Similarly Pak Benny, founder of the mental health NGO “Into the Light” of Jakarta, stated “We, most of Indonesians, perceive mental illness as a spiritual phenomenon; whether it is because you are bewitched by a witch-doctor, or whether it is because you are possessed, or whether it is because you have some kind of bad karma, or whether it is because of God’s curse. You know, things like that.” He

concludes, “It is kind of hard to refer people to psychologists or psychiatrists because everything is thought to be at a supernatural level” (pc, November 9, 2015).

While this perception of psychosis as supernatural has been experienced and written about, in my fieldwork I also encountered instances in which families turned to spiritual healers after having exhausted their options in the healthcare system. The Islamic teacher I interviewed described a patient who had been in a mental health hospital for 19-days, at the brink of the limit for in-patient care, and came to the teacher after he completed what the hospital could offer him. After I asked whether the Islamic teacher ever refers patients to medical care, he responded that patients often come to him after having been to a psychiatrist. He commented, “They are the ones that come here” (pc, November 19, 2015). Similarly, on a home visit to a patient with schizophrenia that I accompanied a clinical psychologist to in central Java, I learned that after having sent their patient to the mental health hospital six times, the family plans on taking him to a *pesantren*, or an Islamic boarding institution. The mother explained that at the *pesantren* the patient could receive both spiritual development, as well as gain practical skills for work, such as training for agriculture or tailoring (pc, November 21, 2015).

It is crucial to consider, then, that families seek spiritual aid not only as a product of perception of the illness as a natural phenomenon, as is the subject of much literature, but also as a product of having already navigated the healthcare system. As the spiritual healer explained, many of the patients he receives were previously placed into hospital in-patient care. For the family I spoke to, not only is the *pesantren* viewed as an opportunity for spiritual and skill development, but, as the patient’s step-father described, “the last way.” In our conversation, he explained “Treatment does not work. He is still the same.” The parents of the patient have difficulty giving him medicine, as he “rarely takes it.” The step-father sleeps across the street

because he fears that the patient might “hit or attack” him during the night. The mother does not sleep much, she explains, as the patient attempts to turn on the music system throughout the evening. The parents have been the primary caregivers of the patient since 2009. Now, the step-father explains, they feel that “there’s no solution” (pc, November 21, 2015). At times, faith in spiritual healers is not solely a perception of the illness, but also a product of having placed faith in a medical system without receiving the expected, or needed, care.

Pasung

I return, then, to the practice of pasung to contextualize the use of chains in family care. While one psychiatrist I interviewed described the act of pasung as “disgusting” and it has been termed “irresponsible” by the Indonesian government, one cannot consider the practice of pasung outside of the context of mental healthcare options, and moreover, the extent to which those are options (Nurjannah, 2014). My discussions in Jakarta with psychiatrists, mental health nurses, policy makers, and the Ministry of Health, as well as my on-the-ground observations of government-operated facilities reveal that while these contexts embrace a systematic form of care, there also exists structural barriers to those whom need access to such care. Hospitals do not accept referrals from pasung and place a cap on the care a patient can receive. Puskesmas are based on a village system in which those who have run away as a product of their condition, or have been displaced as a product of shame, are not accounted for. While some alternative spaces, such as the HIV shelter, reimagine what can constitute care, access to this facility is largely based on luck, as a product of a referral from a friend or family member, and in some cases, as described to me, via Google. The two remaining spaces I observed utilize pasung themselves, in the form of enclosed bare rooms wherein patients remain locked up.

Thus, the practice of pasung often comes when the family's efforts to accessing healthcare have been exhausted. In her ethnography on pasung in Aceh, Tyas writes that most families interviewed stated they would not practice pasung had "they had a better option," articulating the practice as what is "often a last resort" (2008). Similarly, Pak Benny explained, "I've heard from families of pasung that sometimes they are worried about the patient...sometimes it is because they are already burned out. They are already tired about the conditions. Well they just can't do anything about that: they have no idea, they have no proper access to the mental health system."

Pasung, then, can be considered a space of care itself. The chains are applied when families, as Tyas writes, have "exceeded their limit to cope with the situation" (2008). Dr. Rama explained to me that often the act of restraint is driven by such an attempt at care, saying that families often tell him, "We did the restraint because we love him or her so much." Tyas' work supports this motivation as well, writing how one family member confessed '...if he has to die, he will die here...on our lap and we know what happens to him and will treat him properly' (2008). Beyond the families feeling as if they have exceeded their efforts to access the healthcare system, healthcare professionals and researchers themselves support this argument. Concluding their findings concerning pasung in Aceh, Puteh et. al write: "Faced with the problem of looking after a severely mentally ill family member, concerns about risk to the mentally ill member or to others, and inaccessible, unaffordable, ineffective psychiatric treatment services, many families (and village community leaders) have little option but to physically restrain the ill family member" (2011). Similarly, Dr. Irmansyah argues that pasung should not be interpreted as a failure of the family, but as a failure of the government, stating:

The ability of the government to provide mental health service, to provide intervention for them, is also an important factor because for many pasung cases, they already have been in the treatment before. It means that they know this is a disease, they have tried to bring the patient to the hospital and maybe they feel that it is not easy to access the mental health service. Then they stop doing that and they practice pasung. The government failed to fulfill the basic needs of mental health services. The basic needs of mental health services is not filled by the health system (pc, November 11, 2015).

Often having navigated the healthcare system before, families who practice pasung do so when their efforts have been tried and they've failed to have, as Dr. Irmansyah describes, their "basic needs" met. The act of applying chains can be seen as a response to a system that families either cannot enter, or, alternative forms of care that families do not want their patients to be released into.

Conclusion

While the depictions of pasung displaying chained frail hands and lock tired bodies trigger attention to gaps in mental healthcare and motivate movements such as Free Pasung, these images need to be contextualized in the mental healthcare system they are situated in. These images left me confused and frustrated this past academic year, as I struggled to make sense out of what would drive a family to lock up a loved one. My interviews and fieldwork have pushed me to see that this is not the question to be asked. Rather, one must consider the context in which pasung is practiced.

Faced with a limited access to and duration for hospital care, an exclusive foundation of inclusive primary care, and alternatives that either utilize locked systems themselves or are obtained as a product of luck, families turn to pasung in attempt to provide the care that they have failed to receive from the healthcare system.

When other options for care are not provided, the chains must be considered as a form of care in themselves. Thus, before the chains are broken, there needs to be consideration as to why they are applied.

Recommendations for Further Study

For further study on the decision to apply pasung, and the intersubjective processes experienced by families, I highly recommend Nuning Tyas' 2008 thesis "Pasung: Family Experience of Dealing with 'The Deviant,'" set in the context of Aceh, Indonesia, as she voices the challenges and complexities that come with the decision to apply pasung. I also suggest reading any and all work by medical anthropologists and sociologists Bryon and Mary-Jo Good of Harvard Medical School, whose ethnographic literature inspired me to study in Indonesia. Specifically Professor Bryon Good's "Phenomenology, Psychoanalysis, and Subjectivity in Java" (2012) discusses the importance of understanding the political context that shapes or silences experiences with mental health, while his 2010 work, co-authored with Professor Subandi of Universitas Gadjah Mada, "Is 'Chronicity' Inevitable for Psychotic Illness? Studying Heterogeneity in the Course of Schizophrenia in Yogyakarta, Indonesia," discusses the need to consider variations in experiences of mental illness both within and across cultures. In light of the Ministry of Health's priority to integrate mental health services into primary healthcare, it is also crucial to continue looking at how these plans unfold and for whom these services will be accessible to.

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Appendix I

Interview Information:

Dr. Rama Giovani, Indonesia Mentality Care, Founder and Psychiatrist, Jakarta, 8 November 2015.

Arrista Trimaya, Parliament, Legal Drafter of the Mental Health Law, Jakarta, 9 November 2015.

Fatih Waluyo Wahid, Parliament, Commission IX Expert Staff of the Mental Health Law, Jakarta, 9 November 2015.

Fitriana Yuliawati Lokollo, Commission IX Expert Staff of the Mental Health Law, Jakarta, 9 November 2015.

Latifah Hasanah, Commission IX Expert Staff of the Mental Health Law, Jakarta, 9 November 2015.

Woro Wulaningrum, Parliament, Legal Drafter of the Mental Health Law, Jakarta, 9 November 2015.

Benny Prawira, Into the Light, Founder, Jakarta, 9 November 2015.

Dr. Eka Viora, Ministry of Health, Directorate General of Healthcare, Jakarta, 9 November 2015.

Nina Mardiana, Yayasan Galuh, Secretary, Jakarta, 10 November 2015.

Dr. Irmansyah, University of Indonesia, Professor of Psychiatry and Bioethics, 11 November 2015.

Professor Budi Anna Keliat, University of Indonesia, Professor of Community Health Nursing, 11 November 2015.

Pak Fadlan, BRH Centre, Islamic Teacher, Yogyakarta, 19 November 2015.

Dr. Sandeep Nanwani, Universitas Gadjah Mada, Physician, 24 November 2015.

Professor Subandi, Faculty of Psychology of Universitas Gadjah Mada, Professor, 24 November
2015.

Appendix II

Interview #2

Benny Prawira, Founder, Into the Light

Age: 25

Can you tell me about your organization, “Into the Light”?

Into the Light is a community. It is developed by young people to young people. We broaden our targets for not only young people, but for specific populations, high risk populations which includes people living with HIV, people living with cancer, juvenile and LGBT people and every single population that is mentioned in WHO as a high-risk of suicide population.

What kind of initiatives does your organization do for mental health prevention and awareness?

Mostly we do web-based programs for suicide-prevention, we share information about suicide-warning signs, how to talk with suicide-loss survivor, and how to talk to suicide-attempt survivors as well. And we also conduct three types of education: seminars, brief workshops, and training for people to learn in-depth about suicide warning signs, risk factors, how to develop programs, and how to prevent suicide in a personal setting and how to have a suicide post-intervention as well, how to talk to the media, how media should deliver news, how to have a proper brief due to suicide, and how to cope with the grief.

Has the Mental Health Law and its implementation impacted your organization?

When the Mental Health Law was an act we had a symposium at the University of Indonesia. I was participating there and that’s what pushed me to develop “Into the Light.” We did not do anything different after the law was passed because we already noticed about the mental health act and we already know about what needs to be addressed from them. Then we just do our activities and initiatives according to the law.

Opening up a little bit, can you talk a bit about mental health and views of mental health in Indonesia? For you, as a mental health advocate, what is challenging for you?

Actually I am writing my undergraduate thesis on the “Subjective norms as a Predictor of the People’s attitudes to Traditional Spiritual Healers.” That’s because we, most of Indonesians, perceive mental illness as a spiritual phenomenon; whether it is because you are bewitched by a witch-doctor; or whether it is because you are possessed; or whether it is because you have some kind of bad karma; or whether it is because of God’s curse, you know, things like that. And when I try to search for mental health literature in Indonesia, it is quite difficult to find experts who really expertise in mental health literacy and conducting research on it. Basically I do not know what is the exact level of mental health literacy in Indonesia. But I assume it is still at a very low level. It is kind of hard to refer people to psychologists or psychiatrists because everything is thought to be at a supernatural level. I deal with suicidal people and it is the hardest part to refer them to the professionals because they still have a lot of stigma on that. They still think that it is still not something that has to be recovered by drugs or psychotherapy.

Do you think then the main challenge in promoting mental healthcare is this difference in perception of the cause of mental illness and the issue of stigma?

We also have economic issues, and also some people are located in remote areas and there is no proper access. We also only have a few psychiatrists in Indonesia compared to the whole population of Indonesia. We only have one in Papua; we only have one in Sulawesi. We only have few, very few. Clinical psychologists, well there are many of them, but they work at companies because it is always considered that clinical psychologists tend to be the smartest ones, tend to be the most complicated ones, but they are not advantages for your personal life; there are not advantages for your wealth. They don't give so many profit, economic profit to you. That's the economic issue, it's not only for the patients, but for the professionals themselves. Only few of my medical student friends really want to become psychiatrists because of financial issues as well. Economic issues for psychologists, psychiatrists, and the people themselves... Ah, BPJS! The national insurance, the national healthcare insurance. They do not cover any harm caused by suicide-attempts. So if you cut yourself or do some self-harm or almost commit suicide, but it does not end your life, then you will not be covered.

Why is that?

I don't know exactly why but I think it's because they don't have enough knowledge that suicide is a symptom of mental illness. They do not think it is an integral part of health. Actually that's the mind problem of any kind of mental health movement, to integrate mental health as a general health. It is seen as a separate thing, as if it is your own mentality or your own type of behavior.

I'm sure you've heard of pasung, or the act of restraining patients. Can you talk to me about what you know about pasung, and why a family would resort to that if there is mental healthcare in place?

I've heard from families of pasung that sometimes they are worried that the patient will harm themselves or harm others as well, and sometimes it is because they are already burned out. They are already tired about the conditions. Well they just can't do anything about that: they have no idea, they have no proper access to the mental health system, and sometimes it's also about the stigma, they feel shame to have a family member who acts that way.

So what do you see as solutions to these mental health challenges?

Slowly we must build more access. The problem is the proper and cheap mental health services that are also friendly to all people because I know there are some that are not inclusive even to LGBT people, even to some people who are living with HIV symptoms. Those with double-stigma will be more difficult to access mental health services because they think that there the psychiatrists or psychologists will condemn them instead of solving their problems, and not only that, but also the economic cost and financial issues must be properly noticed as well for the poor people. And we need more awareness from society. It would be useless and in vain if we have the best mental health system, but the society still has that stigma. So both sides: the government must provide the best proper mental health care that is affordable as well and the society must have a very clear view on this.

Thank you! Is there anything I have not asked you that you would like to add?

The traditional healers must also be educated that there are some problems that they cannot manage, such as the mental illness. They cannot tell that every mental illness is caused by the evil spirits or evil magic or things like that. They have to be educated as well.