Ragapadmi and the First Leper: A Critical History of Leprosy Transmission in Madura, Indonesia

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Abstract

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This thesis explores the interconnections between oral traditions and global health issues around leprosy. A folktale from Madura Island, Indonesia, telling about a princess named Ragapadmi who was expelled from her palace due to suffering leprosy, is the main focus in this study. The area studied, Madura Island, Indonesia, is known as one of the highest leprosy endemic areas in the world, which places Indonesia in the third place of international leprosy rankings in 2015. In this thesis, I study the movement of the Ragapadmi story from an oral tradition, which contains selected memories from the past time in Madura, to documented publications that were used by the Dutch administrators as a part of health propaganda to natives' unique perceptions regarding leprosy which gives a stigma-free environment for leprosy sufferers in Madura. Studying this tongue to paper to mindset movement of a folktale, as I found during this study, is beneficial for the development of medical studies, specifically in the sub-fields of epidemiology, health propaganda and medical ethnology.

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Chapter I

Prologue

Ragapadmi paparabnya, wus lami hantarane, katrappen kagila-gila kebak seluruh hangga, datan wonten selangnipun balarongngan ganda nira.

[Her name is Ragapadmi. For a long time, she has suffered from a repulsive disease, many wounds appear on her body and skin, and her body smells unpleasant too.]

Bangsatjara-Ragapadmi, Carijos Asal Saking Madhura (1933)

In this study, I explore a rarely discussed theme of the intersection between oral traditions and global health through a set of historical and ethnographic analyses centered on the issue of leprosy, also known as *Morbus Hansen* or *Hansen's Disease*. This work explores how the disease is remembered and perceived by various actors—natives on the remote island stigmatized as a leper island, educated natives, and administrators—in Madura Island, in a region that is now part of Indonesia. The folktale that I focus on in this study is a popular folktale about a princess named Ragapadmi who was suffering from leprosy and was banished from her palace. She was buried on a small island named Gili Mandangin, eight kilometers off the coast of Madura Island.

I use the story of Ragapadmi and the story's movement between oral and written forms, including the publications of Ragapadmi, as a way to understand the transmission of leprosy into the area, the original perception of leprosy held by the natives in the area, and its collision with scientific and political interests of the Dutch as the colonizer in the area. The first chapter, *Prologue*, deals with the theoretical, historical and factual background of this study. In the second chapter, *Ragapadmi and the First Leper in Madura*, I propose a question about who the first leprosy sufferer in Madura was. From an epidemiological perspective,

understanding the first sufferer is an important element for the study of leprosy transmission in the endemic area because the contagious disease will not present in one area if the carrier of the leprosy bacteria *Mycobacterium leprae* is absent. Is Ragapadmi the first sufferer in Madura? Can analysis of the folktale bring valuable clues on answering who was the first leprosy sufferer in Madura? Who is to blame for the uncontrolled spread of leprosy in Madura? Or, should we be sympathetic to him or her?

In the third chapter, *Ragapadmi and Failed Dutch Propaganda*, I shift my attention from the folktale to the publication of the folktale. I analyze a variety of written versions of the Ragapadmi folktale published during the Dutch administration in Madura to understand the importance of these publications to the Dutch colonial interests and Dutch imperial discourse, specifically in the field of health promotion. I trace the influence of the Europeans' science in the making within the process of building the body of knowledge about leprosy among the natives through the teaching of Ragapadmi folktale.

Chapter four mainly discusses my field observation report on the Ragapadmi folktale and leprosy within contemporary discourses of the Madurese. I present different perspectives held by the Madurese: those who were educated in formal educational institutions and those who lived on a leper island near Madura, Gili Mandangin. I coin the term *alternative* rationality to capture the unique perspective held by people in Gili Mandangin. In the last chapter, I present a short reflection of my research on what next steps to take for advocating further discourse concerning scientific and alternative rationality as well as for helping the rehabilitation process of people affected by leprosy within their own society. I also discuss the different rationalities that existed during the history of leprosy in the Indonesian archipelago.

To conduct this study, I traveled to the Western part of Madura, covering Bangkalan and Sampang regencies and a small island Gili Mandangin near Sampang where the story of Ragapadmi is popular among the locals, during the Summer of 2017. From this travel during which I used the Ragapadmi story as a calling card, I documented various versions of the folktale, interviewed local people about their beliefs about Ragapadmi and how their beliefs influence their perception of leprosy. Since I focus on the issue of leprosy in this study, I tend to name the folktale "Ragapadmi", after the female character, Ragapadmi, who suffered from leprosy. Some people also refer to this story as the history of Gili Mandangin because there are two graves on the small island that are believed to be the graves of Bangsacara and Ragapadmi. The island has long been known as a leper island since a long time ago, even though I have not found any official colonial documents mentioning Gili Mandangin as an asylum for leprosy sufferers. The label of Gili Mandangin as a leper island, I assume, is a result of the stigmatization caused, in part, by the Ragapadmi folktale.

For the writing of this study in which I employ many references either as primary sources or as secondary sources that are written in various foreign languages such as Dutch, Indonesian, Javanese, and Madurese, I take full responsibility of all translations into English. I also avoid lengthy theoretical discussions and complicated wording in this thesis since I want this thesis to flow as a form of storytelling. Hopefully, by writing this thesis in such manner, I can reach a wider-range of readers: those from an academic milieu and those from an isolated leper island and those in between.

Ragapadmi story in Dutch publications

Ragapadmi is considered to be the most popular folktale from Madura during the Dutch direct administration in Madura during 1850 – 1942 (Uhlenbeck, 1964: 179). The folktale was firstly published on the occasion of the 6th International Congress of Orientalists

in Leiden, 1883, by A. C. Vreede for in his linguistics article in *Bijdragen tot de Taal-, Land- en Volkekunde van Nederlandsch-Indië, 1883 (7) [volgno 2]*. This folktale, under the title of *Bangsa Tjara, Madoereesche dongeng* (Bangsa Tjara, a Madoerese Story), was only a short excerpt of the folktale and was presented using the Madurese language. In 1917, the full version of the folktale was published, still in the Madurese language yet written with the Madurese script (*hanacaraka*). The authors of this version were A.C. Vreede and Soemawidjaja.

In 1932, this folktale reappeared in scholarly communities after Th. Pigeaud's academic article, *Bangsatjara en Ragapadmi, Een Verhal van Madoera* (Bangsatjara and Ragapadmi, a Story from Madura), was published in the journal *Djawa 12*. Different from Vreede's account that was written in the Madurese language and script, Pigeaud's publication was in the Dutch language. Given that the folktale was written in Dutch and was published in an academic journal which was exclusively read by a limited number of people, the targeted readers were surely Dutch scholars and policy-makers.

Later in his *Literature of Java* (Volume I, 1967: 136), Pigeaud classified this story, pointing at his own 1932 account, as "comparable with nineteenth-century Central Javanese historical novelistic literature like Prana Citra and Jaka Paŋasih." Pigeaud's argument contrasts with previous Dutch scholars' comments on the authenticity of the Ragapadmi folktale as an original tale of the Madurese. Vreede in his 1883 article states that the absence of a *tembang*-like form of the folktale shows that it is not under the influence of the Javanese literature. Another scholar, J.P. Esser (1892: 42) in his *Onder de Madoereezen* supports Vreede's statement, saying that there is no similar story like the Ragapadmi story in Malay. For sure, Pigeaud's account of the Ragapadmi folktale was not intended for helping the preservation of the Madurese oral tradition. This account, which was followed its Javanese

translation in 1933, was intended for other purposes that we will discuss more in the following chapter.

During the European colonial era, studies of indigenous oral traditions were believed to be fruitful for supporting colonial political and policy agendas. Knowledge of local history and tradition, naturally inherited through generations, is very crucial for the aim of implementing public policies and shaping public perspective. James Scott (1985: 36) argues that oral traditions' documentation of a society is regarded as a conspiracy between academia and government that is "simply not well equipped to uncover the silent and anonymous forms of class struggle that typify the peasantry." Rather than to helping the preservation of the tradition, indigenous tradition documentation done by colonial administration contributes to the stereotyping and classification of the natives in a negative way. This type of historical documentation was unable to be freed from the colonial government intervention, as Osterhammel (2010: 95) claims:

Indeed, there is much to support the view that the worldwide expansion of mass media and western consumer supplies in the past decades has transformed non-European civilizations more than centuries of colonial cultural modification. This cultural modification was initiated by the colonial state, which intervened in indigenous cultures with varying degrees of intensity, depending on the intent and strategy of colonizing.

Among many other scholars of colonialism, Laurie Sears (1996: 10) uses the term *colonial discourse* to point out the way colonial "scholars, administrators, and missionaries" define the natives' identity and tradition in their own imagery for Europeans consumption, and later, this European-influenced imagery is re-introduced to the natives who received and passed along the new, often negative, identities and traditions. In addition, Osterhammel (2010: 107) notes that colonial discourse can be investigated in "a large palette of source material: missionary reports and administrative files, memoirs, travel accounts and fictional literature, the press, propaganda pieces, and academic investigations from many fields

including geography, ethnology, and oriental philology." This idea of *colonial discourse* behind the Dutch publication of the Ragapadmi folktale is the main discussion in this thesis, primarily in the third chapter.

Of medicine and history

The history of medicine is believed to be very important for the development of medicine itself and the field of medical studies. A non-interdisciplinary approach to medical studies, which is focusing solely on laboratory experimentation rather than social, ecological and historical realms of a disease, arguably led to a cultural crisis of identity within the field of public health and made it less humane. This condition is described by the neurosurgeon Harvey Cushing (1930: 30) as a medicine that "has become so scattered and subdivided." John Warner (2011: 92) supports the multidisciplinary approach of scientific medicine by defining the history of medicine as a

vehicle for rehumanising modern medicine, a counterbalance to reductionist hubris in the individual physician and a cohesive force binding medicine together in the face of splintering tendencies of an increasingly specialized medical world.

This study examines the possibility of folk-literature and oral history in helping physicians and doctors approach the challenge of leprosy. While laboratory-approach studies primarily discuss the disease and the medicine, they often forget that the social elements of leprosy, including stigma, social rehabilitation, and the sufferers as a part of the leprosy ecosystem, are the ones that also hinder the eradication of the disease. Global efforts to eliminate leprosy through MDT (multiple drug treatments) are still failing, in my opinion, not because the number of leprosy cases reported remains unchanged in several countries, but because the rehabilitation process does not run very well. Rehabilitation will be regarded as successful only if the patient can return to their home and their neighbors without any

problems and hindrances.¹ Contemporary leprosy sufferers, even though cured, are still stigmatized within the society simply because the physical changes and disabilities caused by leprosy remain visible. People may easily see finger mutilation or facial deformity of former leprosy sufferers and think that they still carry the disease.

This study will be useful for helping either health workers or common people to understand in what condition leprosy was spread to one region, and why people perceive leprosy in non-supportive ways. This study, when presented using different forms like a comic book, movie, or other popular and accessible media, might be applicable for helping the elimination of the stigma of leprosy, and further, helping the rehabilitation process of the former sufferers in their society of origin. This study, although specifically conducted in the Madura region, is relevant to health promotion efforts in other regions. Now I will turn to the Ragapadmi story itself to show how the story has embedded the problem of leprosy sufferers in certain areas of Madurese society.

Global history of leprosy

Leprosy in contemporary scientific explanation is a chronic skin disease caused by the infection of contagious bacteria named *Mycobacterium leprae*. The bacteria infect nerves system and affect skin and joints. Until today, *Mycobacterium leprae* is still non-cultivable which makes impossible any scientific efforts to find its vaccine. It is widely believed that the only agent for *Mycobacterium leprae* is human, and this disease is spread through intensive human interaction. Another unique characteristic of *Mycobacterium leprae* is that it has a

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¹ J. W. Brandsma (2016: 69) *Rehabilitation of Leprosy-affected People: An Overview.* While this article becomes one of my references in this study, I actually disagree with Brandsma's belief that deformity should be made unseen hidden through medical efforts. For me, the ultimate rehabilitation is when the society accepts exsufferers without consideration of his or her physical condition. In my personal opinion, reconstructive surgery should not necessarily be applied to ex-sufferers; it should be an option only if the physical impairment hinders the ex-sufferers from working or doing routine activities, but not only for avoiding the stigma of the disease.

very slow growing period, measured in 2 weeks for making division. This enables early detection of leprosy except through biopsy, and also answers why the first symptoms of leprosy might appear after 5 to 15 years of contagiousness.² It is also predicted that the existence of one leprosy sufferer in one area might spread the disease to 20% of the total community.³

Throughout the history of human wellness, leprosy is regarded as a haunting nightmare. This terrible disease, characterized by the physical annihilation of the sufferers, was often associated with condemnation, isolation and social segregation. This disease was often linked to traditional beliefs, colonial interests, and religious and humanitarian missions, in addition to continuous medical efforts in identifying the causes, formulating treatments and preventing the spread of the disease. There are a lot of previous references approaching leprosy as not merely a medical issue, but as a social issue due to its negative stigma. Zachary Gussow (1989), in Leprosy, Racism and Public Health: Social Policy in Chronic Disease Control offers interesting insights on how leprosy presents in the United States yet does not attract any academic interest. He argues that the absence of comparative studies—and other kinds of studies—regarding leprosy is caused by the universality of negative myths about leprosy. David Arnold's (1993) account, Colonizing the Body: State, Medicine and Epidemic Disease in Nineteenth-Century India informs us about British colonial efforts to control the spread of leprosy in British India and how these efforts were not in harmony with the practice of Ayurveda (Indian traditional medicine). This dissonant relation was caused by the negative perception held by the British on leprosy and on the natives. Another account, Eric Silla's People Are Not the Same: Leprosy and Identity in Twentieth-Century Mali (1998), provides

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² Britton and Lockwood (2004:1210) mention the average period of 10 years for leprosy bacteria incubation before the symptoms appear on sufferers' body. This delayed presentation "results in higher rates of deformity."

³ See *Pusat Data dan Informasi Kementerian Kesehatan Republik Indonesia* (Infodatin) published by the Ministry of Health of the Republic of Indonesia, 25-01-2015, about *Kusta* (Leprosy), p. 7. I received similar information from the online course on Increasing Awareness on Hansen's Disease that I took in December 2017.

an important assessment of the case of leprosy within one ethnic group of Malian people. He traces how social dynamics, such as migrations, colonialism, and political evolutions complicate the spread of the stigma and the disease of leprosy. These accounts show that leprosy and negative stigmas cannot be separated from studies regarding leprosy in any parts of the world.

During the European Middle Ages, leprosy was known to the public as a disease called *tzaraath*, as referred to in Leviticus 13:2. Although many believed that leprosy was not the same disease as *tzaraath*, people assumed that they both had similar symptoms. Regarding the accusation of the Bible as the source of leprosy's stigmatization in the modern world, scholars from Alexandria in the third century are blamed as responsible due to their erroneous translation of Leviticus. Those scholars, according to Brian H. Bennet, et al. (2008), translated the Hebrew term *tsara'ath* that was actually associated with unclean acts and conditions into *lepra*, a Greek word used for certain skin conditions such as scaly, flakes and barks. This erroneous translation led to a prolonged stigma in the 19th and 20th centuries when the Europeans brought their religious teachings into their colonized regions. Another rationale which supported this religious teaching of stigmatized disease was because past civilizations did not understand the 'capricious' cause of the disease and were unable to cure this 'intractable' disease.⁴

The discovery of germ theory in the beginning of the 19th century and followed by a claim made by a Norwegian physician, Gerhard A. Hansen (1841-1912), changed the global perceptions of leprosy. In 1873, Hansen learned that this disease was caused by a contagious agent in the form of a bacillus, called *Mycobacterium leprae*. Departing from Hansen's

⁴ I borrow the words *capricious* and *intractable* from Susan Sontag's famous metaphoric description of cancer and tuberculosis. Susan Sontag has made a major contribution to theoretical developments regarding unknown diseases and their metaphorical recognition within society through her books, *Illness as Metaphor* (1978) and *AIDS and Its Metaphors* (1989). She challenged the public's tendency to blame the sufferers of those mysterious diseases instead of supporting them morally.

discovery, and after realizing that the disease was expanding into their colonies, the Europeans, who had political interests in almost every part of the world at that time, initiated the First International Leprosy Conference in Berlin in 1897. The conference was an attempt to formulate steps to be taken globally to prevent the spread of leprosy. The conference recommended that leprosy patients should be kept away from their communities to reduce the possibility of transmission. This recommendation became the beginning of the emergence of legal leper asylums and leper islands in Africa, Asia, the Pacific, and Latin America, which were closely associated with efforts to move the natives out of the comfortable places where they used to live. The Europeans haphazardly implemented the conference recommendation by getting rid of not only people with leprosy but also natives with ordinary skin diseases, unrecognized diseases, and even those who were physically ugly or imperfect. The rediscovery of leprosy in the 19th century, when the sufferers were mostly natives in colonies near the Equator, identified leprosy as a *tropical disease*, ignoring Norway, which was also an endemic area of leprosy.

In many contemporary academic—mostly scientific—accounts, leprosy is mentioned as *Morbus Hansen* or *Hansen's Disease* to celebrate the 19th century scientific achievement in understanding the ancient disease. However, for the writing of this study, I choose to use the word *leprosy* rather than the less-stigmatized *Hansen's disease* since I explore the social aspect of the disease including its mystery and stigma, as well as its horrid impact on past society. *Hansen's disease*, as Maria Diokno (2016: n.p.) suggests, "speaks of cure and

⁵ See: Zachary Gussow, Leprosy, Racism and Public Health: Social Policy in Chronic Disease Control, 1989; Sheldon Watts, Epidemic and History: Disease, Power, and Imperialism, 1997; Michael Worboys, The Colonial World as Mission and Mandate: Leprosy and Empire 1900-1940, 2001; and Sobana Shankar, Medical Missionaries and Modernizing Emirs in Colonial Hausaland: Leprosy Control and Native Authority in the 1930s, 2007.

⁶ This statement is based on Peter Boomgaard, 2007:26, with a reference from *Daghregister* 1682:27.

⁷ An important account that discusses the naming of leprosy as a tropical disease is Sheldon Watts, *Epidemic and History: Disease, Power, and Imperialism*, 1997.

optimism rather than helplessness and certain decline". Leprosy discussed in this study might cover all skin diseases stigmatized or wrongly-addressed as leprosy, even though the disease is not caused by the leprosy bacteria.

Leprosy in Madura

Madura Island, Indonesia, in recent times became the center of global attention due to its abundance of leprosy cases. According to the World Health Organization (2015: 461-476), the documented new cases of people with leprosy in Indonesia in 2014 is 17,025, the third largest in the world after Brazil and India. This number also covers 75% of new cases in the Southeast Asia region. From this number, East Java Province contributes 30% of the total number of people with leprosy in Indonesia, in which 35% of people with leprosy in East Java live on Madura Island (*Beritasatu.com*, March 17, 2016). This means that around 1,788 people with leprosy are predicted to live in the 1,641 square-miles of Madura Island or 1.08 new leprosy sufferers in every square-mile.

On International Leprosy Day 2016, WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa, visited Madura to extend global support to leprosy elimination efforts on the island. WHO has set their target on the elimination leprosy in the world in 2020, while the government of East Java Province has set the target a bit earlier to 2018 through Jelita (Jawa Timur Eliminasi Kusta, *East Java Eliminates Leprosy*). The efforts would be considered accomplished if the prevalent number of leprosy sufferers is under 1 in every 10,000 people. Are they on the right track?

David Blok, et al in their research report entitled *Global Elimination of Leprosy by* 2020: are we on the track? have tried to answer that question. They approach the issue of leprosy in the three highest endemic regions in the world: Chhattisgarh (India), Pará State

(Brazil), and Madura Island (Indonesia) by using a simulation tool named SIMCOLEP. The result shows that Indonesia will fail to accomplish the target of 1 sufferer per 10,000 in 2020 (2015: 548). Worse, Indonesia in 2020 will have the second highest number in leprosy cases after India, since Brazil is predicted to successfully push down the prevalent number to 1.62 per 10,000, better than India (2.11) and Indonesia (1.93). Indonesia—in this case, Madura Island—might not reach the target until 2030, the researchers argue.

Although it remains a problem in modern Indonesia, leprosy in Madura is not a newly emerging problem. West Madura, as reported by the Dutch officials for the First International Leprosy Conference in 1897, had the largest number of people suffering from leprosy in the Dutch East Indies. Bangkalan was the region where most lepers were identified. Compared to other regions in the Netherland Indies, Bangkalan garnered the biggest attention from the Dutch government in attempts to prevent the spread of leprosy through a number of efforts to increase public awareness, to provide treatment facilities for leprosy and to establish leper asylums.

⁸ Before it was dissolved by the Dutch colonial government in 1885, Bangkalan and Sampang were within the territory of West Madura kingdom.

⁹ Reported by R.M.Djoehana, a member of the Committee of Leprosy Eradication in the Netherlands East Indië, through his accounts *Overzicht Aangande de Leprabestrijding in het Regentschap Bangkalan* and *Verslag Omtrent de Leprabestrijding in 1939*.

Chapter II

Ragapadmi and the First Leper

Starting the discussion on leprosy transmission in Madura, one specific question to ask is when, and how, it entered the island for the first time. As suggested in previous chapter, leprosy folktale of Madura Island, Ragapadmi, is placed in the central position for the study. Renato Rosaldo as cited by Jan Vansina (1985:158) describes that "oral sources can best be interpreted by using convergent lines of evidence, and not through internal criticism of single testimonies. This principle involves assembling all the possible reports on a single incident." These notions strongly suggest the important role of documenting oral sources for interpreting one historical phenomenon.

This chapter is intended to draw the 'convergent lines of evidences' that make this folktale, to trace historical moments remembered within the story. To reach that aim, I present a telling of the Ragapadmi story from Kyai Sidiq, the *jurkonceh* (guardian) of Ragapadmi and Bangsacara graves on Gili Mandangin, that was told orally to me on June 15, 2017. As the keeper of the sacred grave, and also the transmitter of the life story of Ragapadmi and Bangsacara to visitors who come to the grave, this telling surely has a very wide spread today among other tellings. However, it is important to note that this is not the only version of the folktale, nor to be said as the most legitimate one. Many people that I interviewed in Madura also present different beliefs on the story of Ragapadmi which will also feature in upcoming chapters. Laurie Sears (1996: 18, footnote 39), citing Barbara Hernstein Smith's argument, argues that "the many versions and variants of any tale, in fact constitute the tale." Based on this understanding, Kyai Sidiq's telling should not be

distinguished from other Madurese's variants of the Ragapadmi story; these versions are what constitute the Ragapadmi story as a part of oral traditions.

Ragapadmi story

I want to tell you about the history of two humans buried here. The left one is Bangsacara, and the right one is Ragapadmi, while in this small grave there are two dogs, Ragapadmi's dogs, namely Caplok and Tandhuk. Ragapadmi was the daughter of Sultan Pacangan, namely Abi Dharda. He was from Morocco, and he was very wise, so people called him *Abi*, which means father in Arabic. Many people also called him Bidharba because it was simpler to say.

Kraton (Madurese term for royal palace) Pacangan was located somewhere around Tragah and Kwanyar in the Bangkalan District. But Sultan Abi Dharda also had a small palace for Ragapadmi who lived with her dogs, and it was in Kokop. There is still a building with a bed made from stone and sand there, a bed for Ragapadmi. There is also a very ancient pool near Tragah, where Ragapadmi used to take a bath. If you go to Tragah, you can ask people there about *kolam* (pool) Ragapadmi.

Besides Ragapadmi, Sultan Abi Dharda also had another daughter, the older sister of Ragapadmi, namely Ragawati. For managing his kingdom, Sultan Abi Dharda had three *pateh* (ministers), the first was Bangsapati, the second was Bangsasena, and the third was Bangsacara. Bangsacara was the most loyal and very nice to people, while Bangsapati and Bangsasena were very cruel and ill-behaved.

One day, Ragapadmi was sick because of a kind of skin disease. It was possibly because of *seher* (black magic). The disease was not *kusta* (leprosy) like what many people outside Mandagin said, but only an ordinary skin disease. Ragapadmi was very beautiful, many princes from other areas came to marry her, but she refused them, so one of them then sent black magic. Sultan Abi Dharda invited many *tabib* (medicine-men), but no one could cure Ragapadmi. When Sultan Abi Dharda started to lose hope, Bangsapati and Bangsasena came. They said that Ragapadmi should not be in the palace because many people would not like to come to the palace due to her bad smell. Sultan Abi Dharda refused, but then Bangsapati said that the best option was to ask Bangsacara to take Ragapadmi home to Bangsacara's house in Aeng Sare. The Sultan agreed. Sultan Abi Dharda asked Bangsacara to meet him. He instructed Bangsacara to take Ragapadmi to Aeng Sare. Sultan Abi Dharda told Bangsacara that he could do anything he wanted to Ragapadmi, and Bangsacara replied that he wanted to cure her.

Bangsacara was actually not an ordinary man. He was the son of Brawijaya, the last king of Majapahit. His name was Aryo Pratikel. He and his brother, Lembu

¹⁰ I think he was very aware of this disease issue, or many people had asked him a question about Ragapadmi's disease before, so he clarified before I asked him.

Peteng, were asked to *aguruh* (study) with Sunan Ampel in Surabaya. ¹¹ After years of studying, both were asked to go to Madura to spread the Islamic wisdom. Lembu Peteng went to Sampang and became *kamituwo* (village chief), while Bangsacara chose to go to a forest near Kokop in Bangkalan and meditated. ¹² After Lembu Peteng passed, Bangsacara went to Sampang to his borther's village and lived with a local family. So, his mother was not his biological mother, it was because he lived at her house so he called her mother.

When Bangsacara and Ragapadmi came to his house in Aeng Sare Village, Bangsacara's mother ordered Bangsacara to find a very rare plant namely *gelang sangkah*. *Gelang sangkah* was a very big tree but what was needed to cure Ragapadmi was only its leaves. Bangsacara remembered that he saw the plant when he meditated in Kokop years before, so he went there to take the leaves.

Bangsacara's mother boiled the leaves as *jemoh* (herbal drink) and also took Ragapadmi to take a bath in a small pool near the village. Amazingly, Ragapadmi's skin then peeled off and a new skin came out. Ragapadmi gained her beauty back. Ragapadmi then told Bangsacara that she wanted to pay him in return and they married after that.

One day, Bangsapati and Bangsasena were asked by Sultan Abi Dharda to check Ragapadmi's condition. They were surprised that Ragapadmi regained her beauty, and they thought that Bangsacara did not deserve such beautiful lady like her. Then they told Bangsacara that Sultan Abi Dharda asked him to go deer hunting on an island named Gili Mandangin. The king asked for fifty deer. Bangsacara agreed, so he went to Gili Mandangin with Ragapadmi's dogs, Caplok and Tandhuk, by holding onto their tails.

On Gili Mandangin, Bangsapati and Bangsasena who followed Bangsacara by boat, suddenly stabbed Bangsacara with their *keris* (a kind of dagger originating from Java and Madura), but Bangsacara was invulnerable. Bangsapati and Bangsasena tried hard to stab him but they failed. So Bangsapati lied to Bangsacara, saying that he was actually asked by the king to murder him. Believing that the murder was under the king's instruction, Bangsacara gave his own *keris* to Bangsapati. Bangsapati stabbed Bangsacara on his chest, and he died. In the process of dying, Bangsacara crawled to a big tree and sat under the tree until he died.

Bangsapati and Bangsasena then returned to Sampang to Ragapadmi's house. Ragapadmi's dogs swam back to Ragapadmi's house too, and they were faster than Bangsapati and Bangsasena's boat. When Caplok and Tandhuk came to the house, they bit Ragapadmi's *sarong* (traditional lower cloth). Ragapadmi felt

¹¹ Sunan Ampel or Raden Rahmat (1401-1481) was a prominent Islamic scholar in Java and also the member of *Wali Songo* (Nine Scholars) who spread Islam through Java.

¹² The presence of Brawijaya's son named Lembu Peteng who was asked to go to Madura appears in *Babad Jaka Tingkir*. Lembu Peteng, according Nancy Florida in her translation of the *Babad*, was Brawijaya's son from his Cham wife, yet later, this name became "a generic label for illegitimate and unacknowledged royal children". See Nancy Florida, *Writing the Past Inscribing the Future: History as Prophecy in Colonial Java*, 1995: 100, footnote 25.

something bad happened on Gili Mandangin, so she followed the two dogs. She went to Gili Mandangin by using the same way with Bangsacara: holding on the dogs' tails. When she arrived on Gili Mandangin, she was shocked when seeing her husband's body. She ran to hug Bangsacara's body, but then unintentionally scratched her finger on his *keris*. Both Bangsacara and Ragapadmi were actually invulnerable, they died because of their own *keris*. After Ragapadmi died, Caplok and Tandhuk jumped to the *keris* and died too.

One day, Kyai Gemma from Prenduan, Sumenep, was on sail to Palembang for trading. When he passed near Gili Mandangin, the wind suddenly stopped blowing his boat. That is why the island is called Mandangin, from *mandhag* (stop) and *angen* (wind). Then a lot of fish appeared on the sea surface, making a prism-like vortex. Kyai Gemma at that time was also in need of water, so he followed the fish to an island. On the island, he found a very big bird with opened wings covering two dead human bodies and two dead dogs. He wanted to bury them, but he needed water to clean their bodies. Then the bird flew away and landed by a small spring. Kyai Gemma took some water from the spring to clean the corpses, and also stored some for his supply. Then he buried those corpses into three holes. One was for Bangsacara, one for Ragapadmi, and one for both dogs. Kyai Gemma marked the graves with stones before going back to his boat. He made a vow that if his business in Palembang went very well, he would come back and build proper graves.

Because of the *karomah* (specialty) of Bangsacara and Ragapadmi, Kyai Gemma's business became very successful. He sold his commodity, which was coconut fiber, with a good price in Palembang. He remembered his vow, so when he went back to Sumenep, he instructed his people to build proper graves and also a small mosque. He also told the ruler of the area, which was Sultan Abi Dharda, about his finding of the corpses. Abi Dharda was very shocked when he learned that the corpses were his daughter Ragapadmi and his loyal servant Bangsacara. Finally he knew that he was deceived by Bangsapati and Bangsasena, so he punished them with the death penalty. They were beheaded and their heads were shown to people in Pacangan kingdom for years.

After building proper graves and a mosque for Bangsacara and Ragapadmi, Kyai Gemma told the story of Bangsacara – Ragapadmi to one of his *santri* (students) and asked him to stay to be the *jurkonceh* of this site. In 1990s, one of Kyai Gemma's *nakpotoh* (descendants) came to this site and he renovated the graves and mosque. At that time, the *jurkonceh* was my grandfather. My grandfather transmitted the story of Bangsacara and Ragapadmi to my father. And now, I become the *jurkonceh*, and I received the real story of Bangsacara and Ragapadmi from my father.

 13 Kyai is an Islamic title for those who are respected for their religious knowledge.

Leprosy transmission in prehistoric era

Many studies regarding the global history of leprosy transmission have concluded that leprosy is an ancient disease from prehistoric time. Marc Monot et al. (2005) in *On the Origin of Leprosy* conclude that the first leprosy sufferer had been among the community in eastern Africa since 100,000 BC. Later on, leprosy was brought with migration waves out of Africa either in the Southern route to the Indian subcontinent, and on to the islands that today make up the nations of Indonesia and the Philippines; or in the Northern route to Asia Minor and the Mediterranean, as well as to China, Korea, and Japan. Both routes were in use from 50,000 – 60,000 BC. On the other hand, some ancient archives mentioning leprosy sufferers appeared in the Subcontinent a bit later than Monot's genomic-based prediction. Leprosy first appeared in Indian books at the earliest in 1400 BC, when the Indians mentioned a disease named *kushta*, a term which is still used in many modern countries, including Indonesia, to refer to leprosy (See: B. H. Bennet, et al., 2008: 1999).

While previous studies, so far, have not given a complete narrative of how the first leprosy sufferers entered the archipelago area in ancient times, folktales give a clearer view. Many folktales about leprosy sufferers are found in some ethnic tribes in the archipelagic area, and most of the folktales present a princess or a beautiful woman as the main character. The Javanese society is familiar with a story about Princess Kadita, the daughter of Prabu Siliwangi from the Pasundan kingdom, who suffered from a skin disease like leprosy, which made her lose her beauty (See Jordaan, 1984). In the Madurese society, princess Ragapadmi who suffered from leprosy has been the most popular story since over a hundred years ago. The Dayaks in Borneo believe a legend about Putung Kempat, a very beautiful girl who had

bangkang mulik or leprosy. ¹⁴ Another leprosy folktale, Princess Tandampalik, a princess from the Luwu kingdom, is very well-known within Bugis society in South Sulawesi. ¹⁵

These folktales have thematic similarities with one folktale believed by the Bunun people in Taiwan as the myth of origin of the Bunun people. The Bunun folktale tells about a princess who suffered from leprosy and was cured by a dog. ¹⁶ The princess vowed earlier that she would marry the one who could cure her sickness. Knowing that it was a dog that cured her disease, the princess kept her promise to marry the dog. Magically, the dog then transformed into a very handsome man and they married. ¹⁷ I notice that a similar process of leprosy healing also appears in the folktales mentioned above. Princess Tandampalik was cured by an albino cow (*sapi bulai*), and later she announced that all Luwu people should respect the *sapi bulai*. Although in Putung Kempat and Ragapadmi stories, the woman character was healed by a young man. Even in the Ragapadmi story, the young man also had two dogs as pets, a bit different from the Bunun folktale where the man was the dog itself. It is only Princess Kadita's story which had a tragic plot. She chose to jump into the Southern Ocean of Java. But then she transformed into a goddess who ruled the Java Ocean. Within the Javanese philosophy, it is believed that every Mataram (Jogjakarta and Surakarta palaces)

¹⁴ Taken from Balai Kajian dan Pengembangan Budaya Melayu, http://ceritarakyatnusantara.com/id/folklore/193-kisah-putung-kempat-#.

¹⁵ The story of Putri Tandampalik was received from an interview with Daeng Kamaluddin, a Buginese on November 10, 2017.

¹⁶ From http://chinesefolktales.blogspot.com/2012/07/princess-who-married-dog-taiwanese.html with reference from Li Fuqing (1999) *Cong shenhua dao guihua: Taiwan yuanzhumin shenhua gushi bijiao yanjiu*, p. 322-324.

¹⁷ In the Philippines, a story about a young woman suffering from leprosy is also popular within society. It was told that, because of her disease, she was ignored by people around her, but she was still very nice to all people. On the day she died, no one even noticed until a mysterious tree grew from her house. The tree bore a strange fruit that was pointy and smelled unpleasantly. But when they opened the fruit's shell and tasted the flesh, it tasted sweet and nice. The people called the fruit *durian*, the king of fruits. This story is told to me by Adrian Alarilla, a Filipino-American movie-maker based in Seattle.

ruler should marry the ruler of the Southern Ocean (known as Nyi Roro Kidul), who was Princess Kadita, before reigning in order to get supernatural legitimation for his throne.¹⁸

These five folktales originated from the same areas passed by the Slow Boat migration. Slow Boat is Austronesians' migration waves through the sea from Taiwan, to the Southeast Asian archipelago as well as the Pacific. ¹⁹ The Slow Boat migration to the archipelago took place around 4,000 BC to 2,000 BC, the same period with the two skulls from Lewoleba and Plawangan that are mentioned above. We can say that leprosy folktales are thematic folktales along the routes of the Slow Boat migration.

Many tellings of the folktales mentioned above are believed by people in those societies, although some of them come with different beliefs about what the suffered disease was. While the majority believes that the disease is leprosy, some of them believe it may be chicken pox or another unexplained skin disease. In relation to this different telling, William McNeill (1976: 144-145) argues that leprosy was often wrongly described as smallpox and measles, which monopolize literary references related to skin diseases. McNeill believes that the circulation of other skin diseases such as leprosy, yaws, and syphilis possibly happened earlier, but due to the spectacular outbreak of chicken pox and measles, the two latest mentioned diseases were more popular in many oral and historical accounts.

¹⁸ R. E. Jordaan (1984) in his *The Mystery of Nyai Lara Kidul:Goddess of the Southern Ocean* also compares Ragapadmi and Nyi Roro Kidul regarding their disease and their importance to the local society.

¹⁹ Some accounts related to the theory of Out of Taiwan Migration are Terry Melton et al, *Genetic Evidence for the Proto-Austronesian Homeland in Asia: mtDNA and Nuclear DNA Variation in Taiwanese Aboriginal Tribes*, 1998; Peter Bellwood, *The Origins and Dispersals of Agricultural Communities in Southeast Asia*, 2004; Albert M. Ko, et al, *Early Austronesians: Into and Out of Taiwan*, 2014.

²⁰ In Hasan Sasra's version of Ragapadmi, the disease is described as chicken-pox. Hasan Sasra is prominent Madurese elder and also a cultural expert. His version is documented in *Madurese Storyteller*. University of Iowa Digital Library. url: http://madurese.lib.uiowa.edu/#/myvideo/item/15. As noted earlier in this chapter, Kyai Sidiq also refuses the popular belief that Ragapadmi suffered from leprosy.

Regarding this different belief, I would argue that it depends on how people respect their leprous heroines simply because telling about their queen as a sufferer of such a stigmatized disease like leprosy will give a more dreadful effect than telling about her as a chicken pox sufferer. This is a practice of masking the information for social purposes. During my fieldwork on Madura Island and Gili Mandangin, I found that some of the Madurese whom I interviewed believe that Ragapadmi suffered from leprosy, while almost all people in Gili Mandangin argue that the disease was only an ordinary disease that they were unable to describe. The same situation might apply to other princess-suffering-from-skin-disease folktales above. In this study, I tend to choose the telling that, in my opinion, has no conflicting interest, which is the one mentioning Ragapadmi as a leprosy sufferer.

Another element, which is important to note is that all leprosy sufferers in the discussed folktales are not ordinary women; they are either a princess or a beautiful lady. Beauty and status, even until this modern era, signify the virtue of a woman within traditional society (Snook, 2011: 60). The presence of a pretty woman who suffered from leprosy in many folktales signifies that, within older perceptions, leprosy is not necessarily assigned to the lower class or condemned people. Even until the 1600s, several native community leaders suffered from leprosy; one of them was the King of Banggai in Sulawesi.



Figure 2.1. The King of Banggai, 1678, described by a Dutch traveler as blind and suffering from skin diseases like leprosy.

Kingdom of Pacangan and the prosperous era of Madura

The Madurese believe that their ancestors were from Java, as shown in their folktale about Raden Segara and his mother, the first settlers on Madura Island. This folktale has been known ever since the 14th century, as noted by Tome Pires in his *Suma Oriental* (written in 1512-1515) during his travel to Madura Island.²¹ Since at the earliest in the 1280s some parts of Madura Island had become subservient regions to many the Javanese empires. It is mentioned in the Javanese Book of Pararaton (written in 1663 AD) that King Kertanegara from the Singasari Kingdom in Java ordered Arya Wiraraja to be the regent of Songennep (now Sumenep, located in eastern Madura) in 1269 AD. The Madurese leprosy folktale, Ragapadmi, is believed to have taken place in the western part of Madura in the same period as Kertanegara's reign. There is a monument in Sampang that has been named by the locals

²¹ At that time, it was common for the Portuguese travelers to compare Madura to Madeira, a small island off the coast of Portugal. Before Tome Pires, the Portuguese under the command of Alfonso d'Albuquerque in Malacca had been wandering the Archipelago and mapping the islands for their voyage to the spice islands. Since the word 'Madura' did not frequently appear in many ancient books or stones either in Java or Madura, probably it was the Portuguese who contributed to the naming of Madura.

as *Lingga Bangsacara*. The monument, dated 1280 AD, is believed to be the evidence that Bangsacara, the husband of Ragapadmi, lived in the area before his death on the small neighboring island of Gili Mandangin.



Figure 2.2. Lingga Bangsacara monument in Sampang

In the area surrounding the *lingga Bangsacara*, four *Akshobhya* statues were found by the Dutch authorities.²² According to Dwi Cahyono, a classical archaeologist from Malang State University whom I met to consult about my findings in Sampang, the monument and the *Akshobhya* statues indicate that there was an ancient local kingdom ruling in the area on behalf of the Singasari kingdom.²³ The year showed by the chronogram crafted on the monument, 1280 AD, is the golden era of Kertanegara and *Akshobhya* is the symbol of Kertanegara. The local kingdom, I assume, is the mentioned Pacangan kingdom in the Ragapadmi story, the kingdom which expelled Ragapadmi.

²² Rapporten van de Commissie in Nederlandsch-Indië voor Oudheidkundig Onderzoek op Java en Madoera 1914, published by Het Bataviaasch Genootschap van Kusten en Wetenschappen. The Commissie is the forerunner of Pusat Arkeologi Nasional Indonesia.

²³ According to Cahyono, the monument actually is not a chair as thought by the locals. Rather, it is a part of temple ruins, indicating that the area was a very important site in the past.

The Ragapadmi story is the only folktale that mentions the existence of a kingdom named Pacangan, believed to be ruling a region at the eastern part of Bangkalan and western Sampang. There is no document explaining when the kingdom was established and when it was abolished. No further information is available regarding the life of the well-remembered Pacangan king, Bidarba, when he started to rule, when he left his throne, and who continued his kingdom. Those details remain a mystery since the life of Ragapadmi gets more attention from the Madurese than the Pacangan kingdom itself. The locals, who live in Tragah and Kwanyar (in the Bangkalan regency), are more able to point to an ancient spring named *kolam Ragapadmi* (Ragapadmi's pool), or a stone mound called Ragapadmi's bed, but no one could point to the exact location of the Pacangan palace.

The region of Pacangan was possibly located in an area that was mentioned by many Chinese travelogues as Ta-Pan. The area of Ta-pan was located outside of Java, but also near Pa-Li (Bali). It connects Jung-ya-lu (Ujung Galuh, near Surabaya which was also an important port in the 11th to 13th centuries) to the eastern areas. This description matches well with the area of the Pacangan kingdom, which was just across the Madura strait from Ujung Galuh. In *Chu-fan-chi*, literally translated as *A Description of Barbarian Nations*, written by Chou Ju-kua (1170-1228), it is described that houses in Ta-pan were similar to houses in China. There was a port, and the trade actively occurred either on the sea or the land. There were many Arabs living in the area, and they appointed a head-man with Arabic origins to be the ruler of foreign traders in the area. This head-man, as described by Chou Ju-kua, was fierce and brave and loved to take wives from neighboring regions who were captured near the island.²⁴

²⁴ Information from *Chau Ju-Kua: His Work on the Chinese and Arab Trade in the Twelfth and Thirteenth Centuries, entitled Chu-fan-chï*, trans. by Friedrich Hirth and W.W. Rockhill. St. Petersburg: Printing Office of the Imperial Academy of Sciences, 1911, p. 84.



Figure 2.3. Maritime Silk Road to Insular Southeast Asia²⁵

Another travelogue also mentioned that during the maritime trade period from China to insular Southeast Asia the Madurese had direct and intense interaction with international traders due to their strategic location (see Figure 2.3). As early as the beginning of the 14th century, a Chinese traveler, Wang Ta-Yuan wrote in his account that the Madurese were very strong and their *jukung* boat "has never been known to break up" (W. H. Scott, 1982: 340). Madura Island was also known for its prosperity among ancient travelers. As mentioned by Tome Pires during his visit to Java and Madura in 1512-1515, Madura:

produces many foodstuffs. They have many horses. They use large quantities of clothes in Madura, made on the island itself, and others that come from outside which they wear. They have no other merchandise, except rice and foodstuffs, and many slaves. (*The Suma Oriental of Tome Pires and The Book of Francisco Rodrigues*, 1944: 227)

In Kyai Sidiq's version of Ragapadmi, the king of Pacangan who expelled Ragapadmi from the palace was a Moroccan. His real name was Abi Dharba, but the Madurese used to call him Bidharba. *Abi* is an Arabic term for father, and he was the father of Ragapadmi. This

²⁵ Source: http://en.unesco.org/silkroad/network-silk-road-cities-map-app/en .

information is not contrary to Chou Ju-kua's writing about the Arabs who became head-men in Ta-Pan. Possibly, the Pacangan kingdom was a region with special authority for securing an international trade route around the Madura Strait, and it was inhabited by many international traders such as Arabs and Chinese.

Mataram's raid and the beginning of a difficult era in Madura

Theodoor Pigeaud (1932) in his introduction to the Dutch-version of Ragapadmi mentions that the ruler of Pacangan was one of the local rulers in Madura who, together with Pangeran Mas (reigning 1621-1624) from Arosbaya kingdom in western Bangkalan, led the war against Sultan Agung from Mataram. H.J. de Graaf (1990) in his *Puncak Kekuasaan Mataram* also mentions the king of Pakacangan (Pacangan) as a brave leader of the Madurese troops during the war with Mataram. However, de Graaf does not provide a detailed description of this brave leader.

Mataram's raid on Madura occurred in 1624 AD, as mentioned in a VOC Daghregister dated 15-09-1624 about a big war in Madura where not only the men but also the women joined the war. Not only attacking the Mataram people, the Madurese women also murdered some Madurese men who cowardly tried to escape the battle. H. J. de Graaf (1990: 84-85) in *Puncak Kekuasaan Mataram* also describes Mataram's preparation and loss during the war with Madura. Sultan Agung instructed two waves of troops to Madura, but the first raid was unsuccessful. After the failure of the first raid, Mataram sent out 80,000 additional troops to Madura, leaving almost no one in the Mataram palace except the king and women. Around 160,000 Mataram troops were on the field, outnumbering the Madurese troops that were only around 100,000. The Madurese troops were from the alliance of Sumenep, Pamekasa, Baliga, Pakacangan and Arosbaya. During the war, Sultan Agung lost his highest

ranking commander, Tumenggung Sujanapura, while three of the Madurese leaders were also killed and the rest were taken captive (de Graaf, 1990: 84-85).

In order to weaken the Madurese, the Mataram troops manipulated the environment on Madura Island by damming the river, poisoning the water, and destroying the crop fields. These environmental manipulations drastically changed the welfare condition in Madura. If Tome Pires in his *Suma Oriental* wrote about Madura in the beginning of 1510s as a wealthy island, the island during and after the Mataram raid suffered harvest failures due to the lack of men to work in the rice fields. After the war, almost no men were left in Madura, so that Sultan Agung instructed a mass migration to Madura. However, this effort did not help to improve the conditions in Madura.

The war with Mataram led Madura Island to become barren, the public welfare decreased, and poverty struck (Reid, 1988: 17-18). Not only in Madura, but Mataram also suffered similar losses, "the lack of men, so that they had not been able to bring the water to the rice fields' during the wars against Madura in 1624, with the result that major rice-growing areas of Mataram itself were barren." (Reid, 1987: 43) There was a decline of population in the Mataram area covering Central and East Java, from around 3,000,000 in 1631 to only 1,035,000 in 1755. The general decline of welfare in Mataram and Madura surely contributed to poor health conditions in the area, which contributed to the emergence of leprosy and other disease outbreaks. Possibly, the first leprosy sufferer in Madura appeared during this hard time, like the Ragapadmi folktale that was believed to take place during the period.

²⁶ Other references are Achmad Su'udi, *Sandur, Penyambung Suara Lidah Madura*, 2008 and Laurence Husson's interview with former Governor of East Java Province, Mohammad Noer, in *Eight Centuries of Madurese Migration*, 1997.

The Mataram ruler, Sultan Agung, also known as Panembahan Senapati, became the most notorious person in the history of Madura. Up to now, there is no street in Madura that is named after Panembahan Senapati or Sultan Agung. In the Ragapadmi story, two antagonist characters appeared who slyly murdered Bangsacara on Gili Mandangin. Their names, as mentioned above, are Bangsasena and Bangsapati, the anagram of Sena-Pati. Decades after Sultan Agung's campaign to Madura, the Madurese set their revenge under the command of Trunajaya. The Trunajaya War (1677-1680) killed the Mataram ruler who was the son of Sultan Agung Senapati, Amangkurat I, and made his successor, Amangkurat II, almost lose his throne before he finally won the war with help from the *Vereenigde Oostindische Compagnie* or the Dutch East Indies Company. Trunajaya was caught and was given the death penalty in 1680. As agreed in the Jepara Treaty in 1677, the Mataram kingdom had to surrender the whole north coast of Java, covering many important trade ports such as Semarang, Surabaya, and Tuban to the VOC in return for VOC's help in the Trunajaya War. (de Graaf, 1976)

Ragapadmi and the first leper in Madura

The Ragapadmi story brings us to a certain set of conditions, which made the occurrence of leprosy widespread in Madura: interaction with international traders who possibly brought *Mycobacterium leprae*, the barren environment which was surrounded by the ocean and poverty. Predictably, the first leprosy sufferers in Madura appeared during the last period of maritime trade around the mid-1600s where the Madurese suffered from poverty and a decline in welfare. The first leprosy sufferer in Madura might have been a rich merchant who traded with international merchants and returned to Madura with the leprosy bacteria, or a poor labor who worked on Chinese vessels. It could also be a foreign trader,

either Arab or Chinese, who came to Madura and chose to reside for good on the island, who interacted intensively with the locals and finally transmitted the disease.

International traders, either the Chinese or the Arabs, were likely to be responsible for carrying the leprosy bacteria to Madura. Many historical accounts blamed the Chinese for spreading many diseases into foreign areas. In his *Malayan Monochrome* (1913), Hugh Clifford points out a mysterious disease, a disease that had actually been detected by the Chinese merchants for a long time, which emerged in the Malayan area and became a big problem there. Vicky Baum in her *Tale of Bali* (1938) also tells that two people who made direct contact with a stranded Chinese Junk later suffered from leprosy. These accounts intrigue me because they indicate that behind the glorious era of the legendary maritime trade route, beyond spices, sandalwood, and cinnamon that triggered international trade in insular Southeast Asia for centuries, there lay the spread of contagious diseases.

The argument that the Chinese merchants were responsible for the spread of leprosy is also supported by Xiaoman Weng, et al. (2013) who conclude that SNP type 1 and 3, endemic in Guangzhou and Zhejiang, are identical with the type of leprosy found in regions where the Chinese merchants traveled for trading during the heyday of the Silk Road. In Thailand, India, and Nepal, parts of the land route of the Silk Road, type 1 is endemic; while in the maritime route areas such as the Philippines, Indonesia, Japan and Korea, SNP subtype 3K and 1D strains are endemic. However, it should not be ignored that the Dutch in the 1600s named leprosy as *lepram arabv* (leprosy from the Arabs), indicating the closeness of the disease with the Arabs living in the Dutch East Indies (see Bontius, 1642: 181).

Poverty and a decline in welfare contributed to the spread of leprosy, which worsened in Madura later on. After Sultan Agung of Mataram's instruction of mass migration to Madura at the end of the 1600s, the population in Madura grew rapidly. The north-east coast

area of Java, including Madura, both of which were suffering from population decline after the war, became over-populated due to this mass migration. In 1774, around 1,496,000 people lived in the area, compared to only 474,000 in the beginning of the 18th century (Reid, 1987: 46). However because of a series of harvest failures, continuing poor soil conditions, and a population boom, poverty was hard to eradicate. Since the 18th century, the Madurese had failed to fulfill their basic needs sufficiently. Madura started to import rice from Juwana (Central Java) and Surabaya, while the local production of maize that was a staple food for the Madurese was insufficient to cover the needs of the Madurese population. Even after Madura Island was under the full authority of the Dutch colonial government in the 1850s, the Madurese were still dependent on other regions for food.²⁷ This decline in social welfare may have contributed to the spread of leprosy bacteria in Madura from the hypothetical first sufferer.

Conclusion

Deep reading of the Ragapadmi folktale, in the end, brings us to a series of historical events in Madurese history that related to the widespread leprosy outbreak in Madura. While Madura before 1600s was known as one of the prosperous regions in the archipelago, Sultan Agung's campaign to Madura in 1624-1625 was the turning point. The war resulted in a tragic condition: dense population with low welfare. This condition may have contributed to the uncontrolled spread of leprosy, while the disease itself was possibly present in Madura before the war, brought by international traders who resided in Madura.

This chapter also shows that deep readings of a folktale may be useful for the study of disease epidemiology. Leprosy, due to its closeness with myths and culture within indigenous

²⁷ See: Luc Nactegaal, Riding the Dutch Tiger: The Dutch East Indies Company and the Northeast Coast of Java, 1680 – 1743, 1996; G. Knaap, Shallow Waters, Rising Tide: Shipping and Trade in Java around 1775, 1996; and Kuntowijoyo, Perubahan Sosial dalam Masyarakat Agraris Madura, 1850 – 1940, 2002.

societies in insular Southeast Asia, becomes traceable through a closer look into many indigenous folktales about skin disease. There needs to be further exploration of how folktales and indigenous narratives, as a form of social DNA, might contribute further toward the study of epidemiology for leprosy as well as other diseases.

Chapter III

Ragapadmi and Failed Health Propaganda

Many Indonesians believe that they were colonized by the Dutch for 350 years. This belief is actually not a hundred percent correct because the region now known as Indonesia is officially colonized by the Dutch government since 1800, even though the Dutch actually made their first step in Java since the early 1600s under a private trading company named *Vereenigde Oostindische Compagnie* for trading with the natives. This company was abbreviated as VOC, while many natives during that time called it just the *kumpeni*, from the word *compagnie* or company. The VOC went bankrupt in 1799, and the Dutch government then took over the areas that the VOC had controlled in 1800.²⁸ The discourse of 350 years of Dutch colonization also signifies one important thing: that there is a really long period within Indonesian history in which the Dutch played a significant role, even to shaping the ways of life and perspectives of the Indonesians in the current time.

In this chapter, I follow the Dutch publications of the Ragapadmi folktale during their administration in Madura. I examine how the Dutch perception of leprosy was imbricated with their colonial goals and the native oral traditions. Analysis in this chapter covers the Dutch's initial encounter with leprosy, their ways to control the spread of the disease through leprosaria policy, their efforts to inject their perception on leprosy and natives segregation through the Ragapadmi folktale publication, and the last, how the Dutch health education system still affects the way people in modern perceive leprosy.

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²⁸ See Jean Taylor, *The Social World of Batavia* (Madison: University of Wisconsin Press, 1983) for the origins and eventual decline of the VOC. The Dutch Government only controlled the East Indies up until World War II, only 150 years. Indonesia was proclaimed as an independent country in 1945, and it won its independence from Holland in late 1949.

The first Dutch encounters with leprosy in Dutch East Indies

When the Dutch explorers sailed to what is today called the Indonesian archipelago for the first time on a ship commanded by Cornelis de Houtman and Peter Dirkz Keijzer in 1595, very little was known by them about what they would find in the area. Dutch conflict with the Portuguese kingdom, their loyal supplier of spices, became their biggest motivation for sailing around the African continent, via the Cape of Good Hope and Madagascar, before they landed in Banten on June 27, 1596. They were warmly welcomed by the locals in Banten, but because of their rude behavior, they were forced to leave. De Houtman then sailed to the east, visited some islands, and headed back to the Netherlands with no spice-trading agreements. He did, however, create a correct map to the islands of spices.²⁹

Cornelis de Houtman did go back to the archipelago years later and died in Aceh. However, his last voyage had convinced many merchants in Amsterdam that the prospect of spice trade from the archipelago would be lucrative in the future. It just took a short time for the Dutch merchants to leapfrog the Portuguese in international spice trading. On March 20, 1602, the Dutch merchants united and founded the *Vereenigde Oostindische Compagnie* (VOC). This company was very special since the operation was fully supported by the Netherlands kingdom. Its ultimate goal was to monopolize the spice trade in Asia. The VOC was also allowed to make treaties and agreements with any important parties, to declare wars, having its own militaries, and to issue currencies on behalf of the kingdom of the Netherlands. In 1619, the VOC made Jayakarta its headquarter after conquering the region from locals and the British, and renamed it Batavia. Afterward, the VOC expanded trade in

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²⁹ Simon Winchester, *Krakatoa: The Day the World Exploded: August 27, 1883*, 2003:15-18. Another reference is George Masselman, *The Cradle of Colonialism,* 1963: 114. One of de Houtman's "rude behaviors" that was mentioned in this book is raping the Madurese women while he was actually welcomed by the locals.

the archipelago, and when the Dutch government took over from the bankrupt Company in 1799, the islands became known as the Dutch East Indies.

Preparing a new trade outpost for Europeans means preparing for all their needs, including the need for wellness. Jacobus Bontius (1592-1631), a physician with a medical degree from Leiden University, was appointed to be the Doctor, Dispenser and Inspector of Surgeons in the Dutch East Indies in 1626, and was posted in Batavia in 1627. In his four years of duty in the Dutch East Indies, he successfully documented various diseases that existed in the tropical area. Some of them were beriberi, cholera, and dysentery. His documentation was published in the four-volumes of *De Medicine Indorum* in 1646. On his documentation, he mentioned leprosy as *lepram arabv*, or the leprosy of the Arabs. Possibly, the disease was suffered mostly by the Arabs who lived near Batavia. Bontius also speculated that scabies could be the early sign of the *lepram arabv*.

Actually, the Dutch and the Europeans were not unfamiliar with leprosy. In Europe at that time, leprosy was called *Saint Job disease* and was often assigned to syphilis or yaws (Boomgaard, 2007: 27). The Dutch might also have heard about the disease from the Spanish who colonized the Philippines.³⁰ Yet, at least until 1665, not many efforts had been made by the Dutch to prevent the spread of leprosy, possibly because they had no idea whether the disease was contagious or hereditary, or because leprosy had not yet been a troubling issue. Compared to the Spanish who conquered the neighboring area in the Filipino archipelago, the Dutch were too late to notice and to respond to the emerging leprosy problem in the Dutch East Indies. The Spanish friars had started to educate the natives in the Philippines, such as

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³⁰ In 1599, a Christian missionary in the Philippines archipelago, Pedro Chirino, wrote about the conversion of many people afflicted with leprosy in Dulag area. It was written that after their baptism, they recovered from their disease and could go back to their community. Fray Francisco de San Antonio also listed several words related to leprosy in his 1624 Tagalog dictionary. See further: Lorelei D.C. De Viana, *Early Encounters between the Spanish Religious Missionaries and Leprosy in the Philippines*, 2016: n.p.

the Visayans and the Ilocos, about leprosy using a religious approach since the beginning of 1600s. These friars, such as Casimiro Diaz, Francisco Alcina, and Fray Benito de Mena, told leprous natives that the disease was caused by sins and bad habits. These friars then introduced the new religion to the suffering natives, converted them, and taught them the importance of taking baths (L. D. de Viana, 2016: n.p.).



Figure 3.1. A painting about the baptism of Cebuano ruler and his wife on April 14, 1521, known as the first baptism in the Philippines. Painted by Fernando Amorsolo.

Around 1665, the Dutch started to feel uncomfortable with the presence of leprosy sufferers who were wandering around Batavia. The Dutch then initiated a shelter near Angke that was intended not only for leprosy sufferers but also for those with skin diseases, physical handicaps, and also for those who were ugly or found begging on the street (see C. Swaving, 1878). The establishment of this leprosy shelter was also connected to the capture of a big number of the Portuguese slaves from Malabar and India who were found suffering from

leprosy (Zuiderhook, 1993: 3). At that time, a Dutch physician named Pieter van Campen working at the shelter was also afflicted with leprosy, but he was allowed to leave the Dutch East Indies to return to the Netherlands and was not sheltered at the leprosarium. It shows that this leprosarium was not intended for the Europeans at all, only for the locals and foreign orientals; i.e. Arabs, Chinese, Indians and Jews.

The beginning of leprosaria policy

In order to solve the leprosy problem in Batavia, the VOC invited William Ten Rhijne to become the trustee of Angke leprosarium in 1677. Before his appointment in the Dutch East Indies, he was a consultant for the Japanese emperor in Dejima Island for Japanese medical research. After his departure from Batavia, he made a recommendation that the Angke leprosarium should be moved because it was too close to the city center. In 1681, he moved the leprosarium to Purmerend Island, off the coast of Batavia. At that time, Purmerend leprosarium was inhabited by 165 sufferers. Ten Rhijne introduced various choices of therapy, such as:

Sweat-secretion was stimulated through hot baths and by swallowing pulverized snakes. Urine-secretion was activated by taking pulverized cockroaches. Furthermore, the bile of pigs was recommended as a laxative and leeches were used for sucking harmful poisons from arm-pits and groins. Castration should result in a strong body and spirit. Meat of black cats and porcupines and the pulverized horn of the rhinoceros were also recommended. The secretion of saliva should be stimulated by inhaling the smoke of candles containing mercury (quijlkaarsjens). The intake of small lizards, so called cicaks, had a regenerative effect. (Zuiderhook, 1993: 3)

Ten Rhijne's methods were still introduced and applied in the leprosarium during the 17th and 18th century. In 1795, there were only 11 patients left, but no record showed the rate of effectiveness of these therapy choices. In the same period, Ambon was regarded as one of the hotspot areas of leprosy. The huge number of slaves brought to Ambon by the Portuguese, in Dutch opinion, was the main cause of the spread of leprosy in the Dutch East Indies. When

the number of slaves decreased in the 1700s, the number of leprosy sufferers was reported dropping gradually (Boomgaard, 2007: 26). Since Ambon was named as a hotspot area of leprosy, in 1701, a leprosarium was built there by the Dutch.

Besides the leprosaria that were established by the Dutch, many native-initiated leprosaria were also found around the Archipelago. The Javanese also adapted the Dutch-style of leprosy isolation by sending leprosy—and other skin diseases—sufferers into a certain area far from the village. Some leprosaria were also found in Sumatera. During his expedition to the Country of Korinchi in Sumatera in the 1770s, William Marsden found a leprosarium consisting of seven sufferers. They were fed by the neighboring villages and were not allowed to leave the designated area or they would be punished by death. No one was allowed to visit them without the local leader's permission.

For Marsden, this leprosarium was surely strange and not authentic, since in his early observation in Nias, he reported that leprosy was a common problem for the people on the island and was thought not contagious. He also noticed that Nias men cured the symptoms of leprosy on their skin with applying *daun kurap* (cassia alata) and such other herbs as well as rubbing gunpowder and strong acids on the affected skin area. However, Marsden also realized that there was another 'species of leprosy', called by the locals as *nambi* "which bears some affinity to this, attacking the feet chiefly, the flesh of which it eats away". The sufferer was driven away

"... from the village he belonged to, into the woods, where victuals are left for him, from time to time, by his relations ... that he may build himself a hut, which is generally erected near to some river or lake, continual bathing being supposed to have some effect in removing the disorder, or alleviating the misery of the patient." (Marsden, 1966: 190)

William Marsden observed that the locals in Nias correlated the *nambi* disease with cleanliness and the low-class people. He also noticed that recovery from the disease was possible, although only in a few cases.

Direct administration in Madura

The year of 1800 marks the changing of the colonizer in the Dutch East Indies. The VOC was declared bankrupt and their assets were taken over by the central Dutch government in the Netherlands.³¹ In the same year, the Purmerend leprosarium was destroyed by the British during the war near Batavia (Swaving, 1878). There is no further information regarding the rationale for this destruction. Possibly it was because of a stray attack, which unintentionally destroyed the leprosarium, or because the British thought that the leprosarium was inhumane. Differing from the Dutch who had no cultural or historical experience with leprosy, the British did. Within British mythology, a leper named Bladud founded the city of Bath, 115 miles from London, in 863 BC.

After 1850, the Dutch colonial government ended their controversial Cultivation System policy and then invited foreign investors to come to the archipelago for doing business, mostly plantation-related. The Agrarian Law (*Agrarische Wet*) of 1870 was one of the colonial government's efforts to attract foreign investors. The Dutch government also forced a direct administrative policy on all regions within the colony, dissolved local kingdoms, and treated local rulers as government officials. Those local rulers were paid monthly, but they no longer had any power or traditional authority. This policy was followed

³¹ The VOC's bankruptcy was mainly caused by mega-corruption scandal carried out by its high-level officials and a series of war with local rulers in The Dutch East Indies. It was shocking since in 1637, the company recorded a value of \$7.9 trillion (inflation adjusted). Even until today, there is no company that can surpass this value. It is worth the total value of the 20 biggest companies such as Microsoft, Apple, Amazon, and Facebook in 2017. When it was abolished in 1799, it possessed a big amount of debt. Source: The Motley Fool, Barry Ritholtz and Sheridan Tilman as cited from http://www.visualcapitalist.com/most-valuable-companies-all-time/.

by a number of acts of resistance from local kingdoms in the Dutch East Indies, such as in Aceh, Bali, Batak, Lombok, and Madura that were threatened by the Dutch expansion into their regions (Ricklefs, 2001: 155-189).



Figure 3.2. West Madura and Gili Mandangin (Pulau Kambing) in Jacob Kuyper's 1894 map (collection of ETH-Bibliothek, http://www.erara.ch/zut/content/zoom/11639912)

In Madura, the direct administration policy was started with the dissolution of Pamekasan Kingdom in 1858, then Sumenep Kingdom in 1883 and West Madura Kingdom (Bangkalan and Sampang area) in 1885. This dissolution, followed by Christian missionary arrivals in Madura, led to a series of rebellions conducted by the Madurese nobles during 1868 until 1890. In 1868, the family of a prominent Christian missionary, Samuel Eliza Hathoorn, became the target of a religious-based murder in Pamekasan that was initiated by two *raden ario*, heirs to the throne of the Pamekasan Kingdom. Although Samuel Hathoorn

was able to escape, all of his family members became the victims of this murder. The accused murderers were executed in Surabaya on July 30, 1869. Another rebellion happened in Bangkalan in 1883 before the dissolution of the Bangkalan Kingdom in 1885. These incidents aroused suspicions that noble families and local elites from the just-dissolved local kingdoms wanted to rebel against Dutch authority (Kuntowijoyo, 2002: 239-248).

Amid the tension between the noble families and the Dutch government, A. C. Vreede introduced his discovery and documentation of the Madurese folktale of Bangsacara and Ragapadmi to the public in the Netherlands. In his academic writing for the *Bijdragen tot de Taal-, Land- en Volkenkunde van Nederlandsch-Indië, 1883 (7) [volgno 2]*, Vreede provided only a small part of the folktale, which tells about the king's conspiracy with his servants to murder Bangsacara on the small island of Gili Mandangin. Possibly, the folktale of Bangsacara and Ragapadmi was used by Vreede as a support for the direct administration policy in Madura and in other regions in the Dutch East Indies. By presenting a story about a cruel and ill-behaved king, Vreede informed the Dutch authorities and the public in the Netherlands that local rulers in the Dutch East Indies were very cruel to their own people. Unfortunately, until the end of 1880s, the Dutch government was most likely not aware of the leprosy that was endemic in Madura.

It was T. Broes van Dort who for the first time reported the leprosy problem in Madura within an international forum of the First International Leprosy Conference, held in Berlin, 1897. In his report widely published in 1898 under the title of *Historische Studie over Lepra: Voornamelijk in Verband met het Voorkomen Dezer Ziekte in Nederlandsch Oost-Indië*, T. Broes van Dort highlighted West Madura (Sampang and Bangkalan) as the hot spots of leprosy in the Dutch East Indies. He presented his finding of hundreds of leprosy sufferers in the area and called for international attention. In his interview with the *Haagsche Courant*

published on November 27, 1897, Van Dort stated that the exact numbers of the leprosy sufferers were possibly higher than the recorded number since the natives in the Dutch East Indies loved to keep their leper family members in their home.

Location	Leprosy Sufferers Number	
	Men	Women
Modjokerto	94	40
Pasaroean	103	40
Bangkil	102	32
Djombang	94	27
Grissee	58	12
Pamekasan	68	49
Sampang	171	77
Bangkalan	298	133

Table 3.1. Leprosy sufferers in East Java in 1897 according to van Dort (1898: 110).

The legalization of leprosaria policy

The identification of *Mycobacterium leprae* as the causative agent of leprosy by a Norwegian physician Gerhard Armauer Hansen in 1873 changed the world's perception of leprosy from a hereditary to a contagious disease. This scientific discovery triggered the rapid emergence of leprosaria all over the world after the First International Leprosy Conference in 1897. There were 12 topics discussed during the Berlin leprosy conference, including notable speeches from Gerhard A. Hansen himself titled "Facultative of Obligatory Isolation?" and François H. Hallopeau titled "Leprosy Brought from the Colonies to the Great Cities of Europe". These two speeches were a foundation for a segregation policy implemented by many colonial countries to control leprosy in their colonies. As mentioned briefly in the beginning of this thesis, the conference also compared two different approaches to control leprosy: Norway's method and Hawai'i's method. In Norway, lepers were treated in local hospitals and not exiled from their society; while in Hawai'i, where the first leper asylum in

the world was built, lepers were exiled and segregated. Ignoring the success of the Norway method, the Hawai'i method was agreed at the end of the conference as the patients with leprosy were mostly from tropical countries.³²

In the Dutch East Indies, the Dutch government took an instant decision to shift the function of Plantoengan Health Center from a military hospital to be the biggest leprosarium in Java. As a follow-up, the Dutch government officially announced a war on leprosy in the Dutch East Indies in 1907. After announcing the contagiousness of the disease, the Dutch government required all sufferers of leprosy—and also the sufferers of other skin and hideous diseases considered as leprosy—to be in compulsory isolation. Until 1911, at least 20 leprosaria had been funded by the government in many areas in the Dutch East Indies, putting aside a number of leprosaria privately initiated by private missionary organizations or the locals.





Figure 3.3. The life within leprosaria. Left picture is from an unknown documentary, a collection of Bridgeman Art Cultural History. The right picture is from a documentary movie about the Dutch East Indies entitled *Mother Dao*, *The Turtlelike*.

³² See: William R. Day, *The Berlin Leprosy Conference*, 1897; Sanjiv Kakar, *Leprosy in British India*, 1860-1940: Colonial Politics and Missionary Medicine, 1996; Subhada Pandya, *The First International Leprosy Conference*, *Berlin*, 1897: The Politics of Segregation, 2003; Ron Amundson and Ruddle-Miyamoto, *A Wholesome Horror: The Stigmas of Leprosy in 19th Cetury Hawaii*, 2010.

³³ See: Bijblad dated. 23 October 1907 nr. 40; Indisch Staatsblad, 1913, nr. 675.

The Dutch had many reasons to establish so many leprosaria all over the archipelago, mostly in Sumatera, Java, and Madura. In addition to controlling the spread of leprosy, leprosaria supported the Dutch's economic (gold) and religious (gospel) interests. Van Vollenhoven in Orang Indonesia dan Tanahnya (2013: 27-28) discusses the violation of the natives' voorkeurrecht (priority right) by the colonial government. Voorkeurrecht was a right that applied even if a person left his land for a certain period of time, he still would have his ownership of the land. The violation of the native's right of land priority is closely related to the Agrarian Law (Agrarische Wet) of 1870 and one of its regulations: the domeinverklaring principle.³⁴ This policy recognized any land that was not under cultivation for more than three years as a wasteland and would be considered as the government's property. As a consequence, when a native-farmer suffered from leprosy and needed to get treatment at a leprosarium for a long period of time, his land would be considered as a wasteland. As a rough calculation, in Surabaya, Pasuruan, Kediri, and Kedu, in 1905, at least 1,252 people with leprosy were isolated from their own land. It means that more than 1000 natives gave away their land to the government as *domeinverklaring* in the four main regions in East Java. It is worth a further study to measure how large the total area of wasteland was from natives with leprosy that had to be turned over to the colonial government.

The leprosaria policy was also closely related to missionary programs to convert indigenous people in the Dutch East Indies to Christianity. Rita Smith-Kipp (1994) in *The Evangelical Uses of Leprosy* reports that the mission recorded impressive numbers at Lao Si Momo, a leprosarium in Karo that was built in 1906. In 1912, Lao Si Momo converted three hundred patients on the celebration day of the 25th year of the mission in Karo, remembered as the biggest number of conversions within a single day in the history of the evangelical

³⁴ *Domeinverklaring* was first introduced only in Java and Madura, but then also implemented in Sumatera (1874), Manado (1877), and Borneo (1888).

mission in the Dutch East Indies. As a result, the contribution for the mission was getting higher. The government, as the main sponsor of the leprosarium, gave 7500 guilders every year. Private contributions also became significant income, worth mentioning are 10,000 guilders in 1923 and 15,000 guilders in 1931. These contributions allowed Lao Si Momo's management to build treatment buildings, hospitals, churches, canteens, and even sports facilities on the 100 hectares of the leprosarium.

In the beginning of the 1900s, as a part of the Ethical Policy implemented by the Dutch central government in the Dutch East Indies, Queen Wilhelmina founded the *Dutch East Indies Welfare Committee*. The committee was instructed to find out why the natives were not as prosperous as the Europeans. One of their findings, and also their primary point, was that the natives had weak physical bodies that were vulnerable to many epidemics. The physical condition surely contributed to their low productivity. The committee recommended that Queen Wilhelmina give extra attention to the improvement of health quality among the natives and to the prevention of contagious diseases.³⁵ This recommendation, in later days, became a solid ground for the establishment of hundreds of leprosaria funded by the Queen Wilhelmina's Prosperity Fund.

When the Dutch opinion of the establishment of leprosaria had consolidated, A. C. Vreede and Soemawidjaja published the full version of the Ragapadmi folktale in 1917.³⁶ This was the same year as the Dutch's *Staatsblad voor Nederlandsch-Indië nr.700* regulating mandatory registration for leprosy sufferers. In 1925, the Inspector General of the Civil

³⁵ For further reference, see a sub-chapter titled *The Welfare of Java and Madura* consisting of the full report of the Dutch East Indies Welfare Committee, compiled in *The Indonesia Reader: History, Culture and Politics*, 2009, edited by Tineke Hellwig and Eric Tagliocozzo.

³⁶Vreede also included in his version that Ragapadmi was suffering from a disease called *parang*. *Parang* in Madura was sometimes associated with a mysterious skin disease. The word *parang* is very close to a Visayan's term *barang* which means, as noted by a 17th century Jesuit missionary Francisco Alcina in *History of the Bisayan People in the Philippines*, "fatally bewitched".

Medical Service proposed a new leprosy bill to make possible the compulsory isolation of leprosy sufferers from their family and society.³⁷

The 1925 decree was clear evidence of the Dutch's fear—and disgust—of leprosy sufferers around them and of being afflicted by the disease. For them, segregating the leprous natives was the best solution. The decree was the follow-up of Bijblad No. 6853 regulating the denial of access to primary school for children with leprosy and also the beginning of inhumane isolation policies into the future. In 1936, a designated home for leprous children opened Semarang. Gomperts, inspector Dienst der was in Dr. the of Volksgezonheid Geneeskundige (Public Health Service), in his interview published in De Indische Courant 15 September 1936, stated,

Childhood age is the most-sensitive period for leprosy infection; therefore, the isolation of the healthy children of lepers will give great benefit. A statistic data shows that 17.5 per cent of children who were raised within a leprosy colony, sooner or later, are infected by the disease, while the percentage for children whose parents are lepers is 23. The isolation must be taken as quickly as possible, preferably immediately after the birth.

The statistic data was used as the rationale for isolating native children of leprosy sufferers before they showed any leprosy symptoms, even immediately after their birth. Surely, the news shows how the Dutch felt afraid and anxious to live amidst the natives, with less consideration about their suffering from the disease, because they—the natives—were regarded as much more susceptible to leprosy than Europeans.

The compulsory isolation policy for leprosy sufferers—including suspected new-born babies who had not shown any leprosy symptoms—was the fruit of the Dutch fears towards the natives and leprosy, and moreover, natives who suffered the-still-mysterious-disease. Sara Ahmed (2004: 69) portrays the mental process of being afraid and anxious:

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³⁷ Mededeelingen van den Dienst der Volkgezondheid in Nederlandsch-Indie, Jaargang XXV, 1936: 4

"[T]he response of fear is itself dependent on particular narratives of what and who is fearsome that are already in place. I have also suggested, the response of fear is all the more frightening given the potential loss of the object that it anticipates. The more we don't know what or who it is we fear *the more the world becomes fearsome*. In other words, it is the structural possibility that the object of fear may pass us by which makes everything possibly fearsome."

The Dutch inability to recognize the nature as well as the transmission of leprosy during their colonization in their Indies was, as described in Ahmed's notion above, what makes their life in the Indies 'fearsome' due to the presence of leprous natives, and even the natives' children within the society. The response taken was isolating and segregating leprosy sufferers away from the more comfortable areas inhabited by the Dutch families.

This compulsory isolation was challenged by a number of humanist-scientists in the Dutch East Indies who considered the isolation inhumane. One such person was Jacob Bernardus Sitanala, the Head of the Division of Leprosy Control. In the end of the 1920s, after his education in Europe as well as his visit to Norway, he formulated a new method for leprosy treatment by imitating Norway's home-isolation method. This method was published in *Nota over de bestrijding der lepra in Ned.-Indie 1936*, co-authored with Mochtar and Sardjito. In Sitanala's method, "patients are required to have their own bed or bedroom, their own eating utensils, and their laundry should not be washed together with non-patients' laundry." This home-isolation method, according to Sitanala, was much more cost-effective than the social-isolation method and leprosaria establishment—and most importantly, it might prevent the sufferers from experiencing negative stigmatization.

³⁸ In Nota over de Bestrijding der Lepra in Ned.-Indie, 1936.

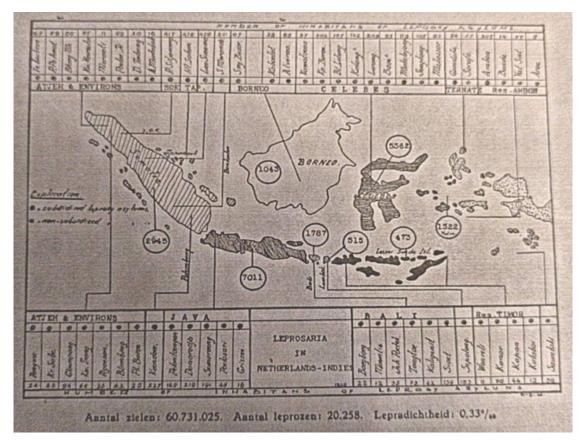


Figure 3.4. The location of Dutch's leprosaria and their total inhabitants in the Dutch East Indies, 1939.³⁹

In the same publication, Sitanala also contributed one article titled *Tradition und Gefuehlsleben*. In this article, he wrote about the presence of the native oral traditions and ethno-medicine related to leprosy. He mentioned two popular folktales from Java about Putri Kadita (known as Nyi Loro Kidul) and a Madjapahit Princess who both were suffering from leprosy. Another folktale was from the Batak region about a young-boy who was cured from his leprosy after stabbing a buffalo, opening its stomach, and staying inside it for several days. Sitanala missed the presence of the Ragapadmi folktale even though the tales he mentioned are similar to the Ragapadmi tale. However, his account was surely intended to convince the Dutch administrators that the home-isolation method would be very successful

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³⁹ Bestrijding in Ned. Indië 1939.

since the natives were familiar with the disease and were very optimistic about the healing process.

Ragapadmi and failed health propaganda

In the 1930s, the health policy of the Dutch East Indies government was reshaped. If previously *Dienst der Volksgezondheid* (the Dutch Public Health Service, or DVG) focused their operation on clinical sectors and hospital care including establishing leprosaria, in the 1930s health propaganda/education started to elevate its position, thanks to John L. Hydrick, the Rockefeller Foundation field officer in Dutch East Indies who was appointed by the Dutch government to become the Advisor for Medical Propaganda. Hydrick applied humanistic approaches to increase public awareness about endemic diseases and hygienic life-styles. He employed movies, known by the natives as *komidhi sorot*, by using dieselpowered projectors for health promotion purposes. In a well-known promotional movie titled *Unhooking the Hookworm*, he introduced the victims of hookworms to native audiences as *Gareng*, a well-known Javanese shadow puppet character who has thin-body yet distended stomach (Stein, 2006: 18). Indeed, the health propaganda programs used the natives' own folk heroes and traditions to ensure their effectiveness.

In 1932, Theodoor Pigeaud, a well-known Dutch Orientalist who spent two decades in the Indies starting in 1924, published his version of the Ragapadmi folktale using the Dutch language in the journal *Djawa 12*, page 186-201. In line with the development of scientific explorations, Pigeaud incorporated some scientific elements and European interests into his folktale. One of those was the mention of *framboesia*, a scientific term for yaws, as the disease suffered by Ragapadmi. ⁴⁰ Pigeaud also introduced guns and pistols for indicating that

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⁴⁰ Until 1940s, leprosy was still wrongly assigned as yaws, and the sufferers were also compulsorily segregated.

the folktale was from the contemporary period. In line with the Dutch efforts to stigmatize the Madurese, Pigeaud also portrayed all male figures as cruel and ill-mannered, even Bangsacara, the hero, was portrayed as a rapist. To meet the Europeans' appetite for sexual sensation, Pigeaud gave a detailed description of how Bangsacara raped Ragapadmi:

He kissed her and caressed her, he stroked her and caressed her; he took her in his arms and kissed her cheek, left and right, and her lips and took her breast. The noble Lady now regained consciousness; she said, weeping: 'Put me down, brother, your arms, my mind is dark, my heart is heavy.' Bangsatjara spoke softly: 'Why is your mind and your heart heavy with darkness? That I may know the fellow.' Ragapadmi said, 'I remember what you once wished for. Sore was your aversion to me. Now, have you kissed me, and thus do come off the sworn oath, Brother, hey, that's what I fear '.

Bangsatjara spoke, 'Not so now, dear, I ask you for forgiveness, love, I want to testify to you my remorse for what I said, and I beg for the consolation of the heart.' He took her breast garment so that it was loose, he kissed her on the feet to the calves and thighs, he caressed her and petted her, hardening her tenacity when he fulfilled his desire.

This description never appears in any known versions of the Ragapadmi folktales. Vreede, for example, only presents a chapter about Bangsacara who tried to convince Ragapadmi to accept his love. In the introductory part of his telling of the tale, Pigeaud argues that this in-detail descriptive style of writing is far more enjoyed by Western readers rather than monotonous and non-detailed style as found in many oral literary accounts. However, this descriptive style of writing will possibly endanger the moral lessons contained by folktales and myths that are orally passed among generations.

Pigeaud also introduced a new method for curing the disease that also did not appear in earlier publication of the Ragapadmi folktale: bathing.

After the widow got the ingredients, she immediately crushed them until it was fine as flour and put them under the sun. Then she took the Princess into the garden and bathed her, then treated her with the scrub. She sprinkled the Princess' wounds, until it was greenish. The widow repeated that day and night. After three days, the wounds were gone and Ragapadmi recovered. Then her skin fell off,

and after a long while it looked like the sea-crab which sheds its skin, or the full moon.

Pigeaud's work garnered significant attention from the Dutch government. In 1933, the Dutch government translated the folktale into the Javanese language and published it as an academic book for *Algemeene Middlebare School* (AMS), or the designated Senior High School for natives from high-level families. In the Javanese translation of Pigeaud's *Bangsacara en Ragapadmi* that was entitled with the same meaning, *Bangsatjara-Ragapadmi*, A Story Originally from Madhura (*Carijos Asal Saking Madhura*), it was told that Ragapadmi, the wife of the ruler of Pacangan kingdom in Madura, suffered a very disgusting disease, as we saw in the epigraph at the beginning of chapter one.

Her name is Ragapadmi. For a long time, she has suffered from a repulsive disease, many wounds appear on her body and skin, and her body smells unpleasant too.

Due to her disease, she was ordered to leave the palace. She was given to the king's lower servant, named Bangsacara. *Cara*, in the Javanese, means thief, burglar, or ill-mannered man. The king ordered Bangsacara:

I have tried so many ways to cure her disease, but failed. Now it has been decided by God. Now, you can take her as your wife, you can have her until the end of your life.

In the end of the story, as noted in earlier chapters, Ragapadmi and her husband Bangsacara were found dead on a small and isolated island named Gili Mandangin.

It is important to note that during the Dutch colonial era, there was no Dutch language Algemeene Middlebare School (AMS) in Madura, so this publication was likely intended for Javanese education, and for a few Madurese who were lucky enough to receive formal education in Java. Until the end of Dutch administration in the Dutch East Indies, there were

⁴¹ Native or the Dutch word *Inlander* was a legal category in the Dutch East Indies along with European and Foreign Orientals which included Chinese, Arabs, Indians, and Jews.

only four AMS or High Schools that were established in Jogjakarta in 1912, Bandung (1920), Surakarta (1926) and Malang (1927). The system was designed to prepare future Dutchminded natives educators. Education was—and still is—considered as a soft and effective approach to shape natives mentality to support the ruler's interest.⁴²

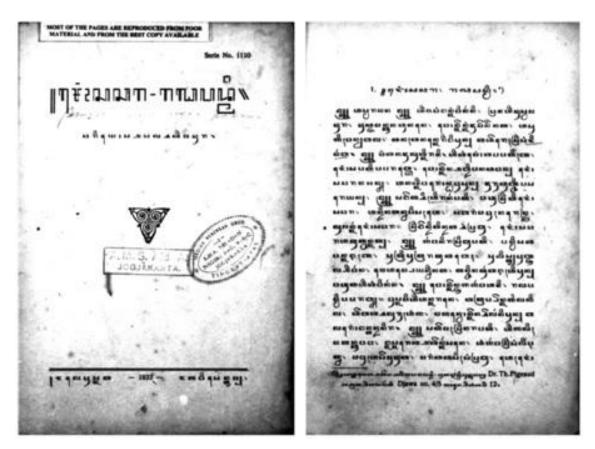


Figure 3.5. The cover and the first page of *Bangsatjara – Ragapadmi, Carijos Asal Saking Madhura*. The footnote states that it is a translated verion of Pigeaud's *Bangsatjara en Ragapadmi, Een Verhal van Madoera*.

The teaching of Ragapadmi, the leper princess from Madura, was possibly part of health promotion initiative conducted by the Dutch government regarding leprosy problems, even though it was done through a different project than Hydrick's health propaganda. This health promotion initiative was inspired by the call for health promotion and education to

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⁴² Soewarsih Djojopoespito in her novel titled *Buiten het Gareel* tells about a man named *Idih* who was an AMS graduate. *Idih* was a native who worked as a civil servant for the Dutch government. With Dutch-style mentality, he acted against his native friends and was very loyal to the Dutch.

raise the natives' awareness of the dangers of leprosy issued by J. J. Van Loghem, a professor of tropical medicine. Unfortunately, this health promotion was not backed up with proper scientific knowledge on recognizing the disease. The Dutch, as well as the Europeans at that time, were incapable of understanding leprosy, at least until the beginning of the 1940s, when most of them lost their colonized territories as the result of World War II. This incapability was acknowledged at the *Intergovernmental Conference of Far-Eastern Countries on Rural Hygiene* held in Bandung, August 3rd to 13th, 1937. The conference agreed that "the scientific knowledge required for this prevention of the disease is not yet completely available; we do not know exactly how leprosy is contracted and transmitted." And they issued the recommendation, "leper colonies should be built and run on the simplest possible lines, every endeavor being made to ensure that the colony is as far as possible self-supporting."

The failure to understand the nature of leprosy transmission resulted in the failure of the health propaganda program through Pigeaud's Ragapadmi teaching. The natives still did not understand what kind of disease leprosy was and what caused its transmission. However, by knowing that the leprous Ragapadmi was isolated in the story, the natives were quite sure that leprosy sufferers should be isolated from their society. The portrayal of Ragapadmi who suffered from a disgusting disease with many wounds and an unpleasant smell directed the readers to see leprosy as very disgusting and inappropriate to live with in society. Her death on a small and isolated island made people believe that the only way to treat leprosy sufferers is by letting them die in isolation. This faulty understanding was continuously taught by AMS

⁴³ In his book, *Tropische Gezondheidsleer* (1933), Van Loghem connects the state of poverty, lack of hygiene, and low education with leprosy. Far before his publication, he had issued some statements on a number of Dutch's newspapers related to the importance of health promotion and propaganda.

⁴⁴ Recommendations for leprosy problem in *Report of the International Conference of Far-Eastern Countries on Rural Hygiene 1937*: 112-113.

graduates to their students, and finally, it resulted in the prolonged stigma surrounding leprosy that is still recognized by many Indonesians in this modern era.

One result of this teaching appears in a dance performance titled Ragapadmi, choreographed by the young artist Kikana Rahman, in *Festival Seni Pertunjukan Adikara Jawa Timur 2008* in Malang. The dance narration presents the stigmatization of the disease, the folktale, as well as Gili Mandangin:

Lonely, Ragapadmi had to face her bad destiny, unfairness, discrimination, and intimidation. She had to suffer this condition she had never wanted. She was isolated on the small island named Mandangin, the southern part of Sampang, in 1305 Çaka or 1383 AD (according to a chronogram found at the site of Prince Bangsacara).

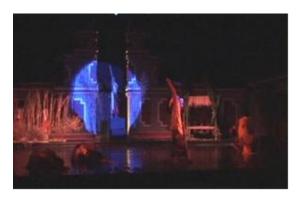




Figure 3.6. *Ragapadmi* dance performance, choreographed by Kikana Rahman. The dance tells about Ragapadmi who was isolated to Gili Mandangin due to her leprosy. (Source: Kikana Rahman's personal documentation).

Conclusion

School curriculum is a part of politics. It is a cost-effective investment that is targeted to shape the thinking of educated people in the future, depending on the ruler's political interests. Education curriculum, shaped first by a colonial ruler, is also where the negative representations of leprosy spread through generations in Java and Madura and many other parts of the Dutch Indies. Ragapadmi appeared as one part of a Dutch colonial discourse that sought to raise awareness of the danger of—and to instill disgust for—leprosy. The Madurese

leprosy folktale, which tells about the isolation of princess Ragapadmi from her palace due to her leprosy, was modified from its original folk versions and then published in 1933 as an academic teaching book for secondary education in the Dutch East Indies.

The teaching of the modified Ragapadmi story has brought us to the conclusion that the Ragapadmi story was used a colonial device to culturally introduce the isolation policy to the native communities. The folktale was introduced and taught to future native teachers in order to spread the European practice of isolating leprosy sufferers; however, the teaching was not properly supported with scientific knowledge on how to cure the disease. It fully relied on the segregation of the sufferers. The result of this failed health propaganda is the negative stigmatization of leprosy perceived by Indonesians in contemporary Indonesia.

Chapter IV

Ragapadmi and Alternative Rationality

In Weapons of the Weak: Everyday Forms of Peasant Resistance, James C. Scott (1985: 321) argues, "Living outside the cities where the agencies of hegemony are quartered, operating largely within an oral tradition that somewhat insulates it from printed media, ... the peasantry is simply less accessible to hegemonic practice." Oral traditions including folktales, in this understanding and in correlation with this thesis, serve as a means for the weak and the left-behinds to resist the hegemonic health policy of the central administration through their formal educational institutions. The previous chapter has explained us how the stigmatization of leprosy in contemporary Indonesia, partially, is caused by the Dutch failed health education through the teaching of the Ragapadmi tale. While the previous chapter focuses mainly on how the Dutch perceived leprosy during their administration, this chapter discusses how the natives in Madura, and the island of Gili Mandangin, share different perspectives on leprosy depending on how they respect the figure of Ragapadmi and her story. This chapter is about what James C. Scott mentioned as resistance of the peasants through oral traditions.

Gili Mandangin as leper island

The island of Gili Mandangin has been stigmatized for a long time as a leper island, a cursed island, or an island clouded with black magic. The leprous Ragapadmi, as believed by many Madurese, was isolated on Gili Mandangin, similar to hundreds of Madurese lepers who were instructed by the Dutch to go to Gili Mandangin. It was in Madura that I met Moja, a Madurese man working as a bank officer and having a Bachelor's degree in economics from a notable university in Surabaya, East Java. He is a descendant of the royal family of the

ancient Bangkalan kingdom, as he has the title Raden preceding his name. When I asked him about leprosy, he said he did not have a clear understanding of leprosy yet. He explained:

I was told about a queen who suffered from leprosy. She was isolated to a small island named Pulau Kambing. The people on the island refused to have her and then she put a curse on the island, so all the people on the island also suffered from leprosy. The queen's name was Ragapadmi.

Pulau Kambing (Island of Goats) mentioned by Moja is another name for Gili Mandangin. These two names are regularly used by the Madurese in daily life. The island is named Pulau Kambing because there are many *kambing* (goats) on the island, while the name Gili Mandangin is connected to the folktale of Ragapadmi.

Other information I learned about the island came from Lia, a university student, who said:

Pulau Kambing is covered by the cloud of black magic. There are many lepers on the island, and I remind you, if you really want to visit the island, don't spit your saliva or they will kill you with black magic.

When I asked Lia and also Moja whether they had been to the island, they answered, "of course not and we will not ever go there." Nur, a senior high school teacher in Bangkalan, gave a very kind suggestion when I told her about my plan to visit the island:

If you really want to visit the island, don't eat any food or drink any water there. You will get leprosy if you do that. I went there while I was a child, I remember there was a *sumur* (well) for lepers on the island to drink. I have a friend who became a teacher on the island for several years, she said that a number of her students are lepers, and they have lost their fingers. The island was a place to isolate lepers in the Dutch colonial era, you surely know Ragapadmi, a queen of a kingdom in Tragah who was isolated to Pulau Kambing because of her disease. She died there and was buried on the island too, side by side with her husband.

Even though the Madurese were in agreement concerning the leper island of Gili Mandangin and the leper queen Ragapadmi, not many of them could explain the characteristics or the origin of leprosy. Some of them believe that leprosy is hereditary, yet it is very horrible because the sufferers would have so many open wounds (*poroh*) on their

bodies. Ilham, a Madurese biologist who graduated from University of Indonesia and was a member of the leprosy eradication program in Madura in 1990s, explained:

In the past, there was a belief that leprosy was curable by stabbing a buffalo and asking the leper to sleep a day or two days inside the buffalo's stomach. The maggots would come out from the leper's body and moved to the buffalo. After no more maggots were left inside the leper's body, his disease would be gone.

Interestingly, the myths and stigmas of leprosy, such as a body full of maggots and many open wounds which smelled bad, were often misunderstood by the Madurese, especially in the area of business competition. I was going to visit a famous fried duck restaurant in Madura, when a friend, Widya, told me not to go there:

The restaurant owner has a brother who is suffering leprosy. He is caged in a cow shed behind the restaurant. If I were you, I would not eat there. Flies land on the man's open wounds (poroh) then land on the food! That's not hygienic, and if the flies land on my skin, I will get leprosy too.

When I asked Widya whether she has seen the leprosy sufferers with her own eyes, she shook her head.

It was my driver who told me that. He also encouraged me not to buy any food from the restaurant. Well, maybe that is only an issue, maybe a wrong issue, for business competition. But what if that is true? So I think it is better to not visit the restaurant even in the future.

The wrong-usage of the negative stigma of leprosy in business competition is surely problematic; however, it is still people on the island of Gili Mandangin who feel the impact of such negative stigmas the most.

The stigma of Gili Mandangin as a leper island was also brought to my attention in the form of a cruel joke. Andhika, a teacher who has taught in Gili Mandangin for 14 years, told me that many new teachers are afraid of eating any food, drinking water or coffee or tea, or even to have their hand kissed by their students after the class. ⁴⁵ It is because those young

⁴⁵ Kissing teacher's hand is a common practice in traditional Indonesia to show respect and devotion of students to their teacher.

teachers, who are mostly from outside Gili Mandangin, are affected by the negative image of the island.

> I used to make a joke on them. There was a time when one of the student's parents came and brought $rujak^{46}$ for all the teachers here, I saw those new teachers actually were hungry and wanted to eat the rujak. But then I told them that the *rujak* seller's fingers were like this," [Andhika was bending his fingers imitating leprosy sufferers' mutilated fingers] "and they refused to eat the rujak. But for other teachers who lived in Gili Mandangin since their childhood, they still ate the *rujak*. And because the new teachers did not eat the *rujak*, I brought the left-overs home, hahaha.

"No Leprosy in Mandangin"

In Madura, Ragapadmi is remembered and stigmatized at the same time. According to Kyai Sidiq, a lot of people, especially on Thursday afternoon, came to Gili Mandangin to make a ziarah (religious visit) to the graves. They recited the Holy Qur'an, prayed, and asked for karomah or the specialty from Bangsacara and Ragapadmi. Before going back to their home outside Gili Mandangin, they took some bottles of water from a spring-well near the Tombs. It is widely believed that the spring is as old as the story of Bangsacara and Ragapadmi, and the water from the spring was used to clean Bangsacara and Ragapadmi bodies before being buried. I once dared myself to drink from the well, and interestingly, the taste of the water was not as salty as other water in Gili Mandangin.⁴⁷

During my 90-minute travel by traditional boat from Sampang to Gili Mandangin, I talked to three Gili Mandagin people. They asked me what brought me to the island. I answered that I wanted to visit Ragapadmi's grave in Gili Mandangin. I explained to them that I heard many stories about Ragapadmi's leprosy and Gili Mandangin's reputation as a

⁴⁶ Madurese traditional salad

⁴⁷ Later, I regretted my decision to taste the water. The spring-well was located within a hut, with a very minimum exposure to sunlight. John Miksic (1999) in Water, Urbanization, and Disease in Ancient Indonesia states that water if stored for a long time either in jars or wells and with a very low exposure to sunlight would be more susceptible for bacterial contamination. I also met a leprosy sufferer just some steps from the well and it was likely that she frequently visited the well as I and other people on Gili Mandangin did.

leper island. Pak Ajjih, the most senior of them said, "There is no leprosy in Mandangin." He then confronted me. He said that I heard a false version of the Ragapadmi folktale and that I came to the wrong conclusion that Gili Mandangin was a leper island.

Many people kept telling false folktales. I don't know whether Ragapadmi suffered leprosy or not, but she was cured in Sampang, in a village named Aeng Sareh. That she died in Gilih (Gili Mandangin), that is true, because her grave and also her husband's grave are in Gilih. But she was just a couple minutes at Gilih before she died.

Ahmad, a teacher in his thirties who was also in the conversation, stated, "Even if the folktale is true, it means that Gili Mandangin was a place to cure lepers, not to isolate lepers. But the real story is Ragapadmi was cured in Aeng Sareh village, in Sampang."

Even though people in Gili Mandangin claimed that there is no leprosy on the island, I did meet several leprosy sufferers on the island. My first encounter with leprosy sufferers was on the traditional motorboat to cross the strait from Sampang to Mandangin. The second one, and the one that I encountered many times during my stay in Mandangin due to her active social interactions, was an old woman whose fingers have been worn away by the disease. Interestingly, the Gili Mandangin people treated leprosy sufferers like they are the same as other people in the village. I did not find the same stigma towards leprosy sufferers as people outside Gili Mandangin have. Leprosy sufferers were not seen as disgusting by people in Gili Mandangin.

According to Andhika, who also guided me during my stay in Gili Mandangin, people on the island called the disease suffered by the old woman as *sompa'an* (oath or curse).

People here have a taboo; they are not allowed to eat *kue cucur*⁴⁸ and *tengiri*⁴⁹. They believe that their ancestors during their voyage were almost lost but suddenly a lot of tengiri appeared and helped their ancestors to find the way to go

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⁴⁸ *kueh cucur* in Malay or *khanom chuchun* in Thai. This sweet dessert is made from rice flour and palm sugar. It shapes like s prism, with thick dough in the middle and thin and crispy at the edge.

⁴⁹ A species of mackerel

to this island. The tengiri when they appeared into the sea surface formed a prism-like vortex, like *kue cucur*. Then the ancestors made an oath to not eat *kue cucur* and *tengiri*, and all their descendants would not too. If one of their descendants breaks the taboo, he will suddenly get a skin disease. It is also believed that men will be more susceptible to break the rule and get a *sompa'an* disease rather than women, because men work as fishermen. I have a friend, when he was out fishing he was very hungry and ate one of his fish. Instantly, he got the karma and suffered *sompa'an*.

In the Ragapadmi story that was brought to me by Kyai Sidiq, there was one certain part which is similar to what was told by Andhika. After Ragapadmi and her husband died, a merchant-ship was passing the island on its business travel to Palembang. When the merchant passed the island, suddenly the wind stopped blowing his boat. Instead, it created a prism-like vortex and turned the boat to land at the isolated island. On the island, he found the two dead bodies of Ragapadmi and Bangsacara, and buried them. He then made an oath that he would not eat any *kue cucur* to respect the prism-like wind vortex.

Leprosy, according to oral traditions in Gili Mandangin, is caused by violating dietary taboo by eating *kue cucur* and mackerels, but this oath or curse will only affect those who have ancestral relationship with the founder of Gili Mandangin who made the oath. Violating the dietary taboo is not necessarily seen as a bad action since it could occur unintentionally. As the result, people in Gili Mandangin do not perceive leprosy as contemptible and disgusting. They live with leprosy sufferers like they are not suffering any contagious and widely stigmatized disease. A young man, *Santreh*, even told me that the old woman—a leprosy sufferer whom I encountered frequently—possesses a supernatural power as she did not feel any pain when her fingers were detached.

I assume people from Gili Mandangin and in their communities were familiar with the existence of people who do not feel any pain when losing his/her parts of the body. This familiarity has also been infused into their version of the Ragapadmi and Bangsacara tale since both were invulnerable to any sharp weapons. I was fascinated and a bit shocked by

Santreh's explanation. It is surely a contradiction to any scientific knowledge, which confirms that leprosy might cause numbness on the sufferers when annihilation takes place. This numbness is what was also felt by the old woman—and other leprosy sufferers in Gili Mandangin. For people who are not exposed to scientific explanations about leprosy, they might think that the numbness is a supernatural power.

Although this perception is not correct according to the medical science, it has provided comfort to leprosy sufferers so they can feel welcomed by their society. People in Gili Mandangin do know how to respect other human beings regardless of their physical condition. This perception is positive, very positive if compared to the negative stigma of leprosy perceived by most of the Madurese and Indonesians—those who are the most exposed to modern science. The Europeans, specifically the Dutch, have a significant role in spreading improper knowledge about leprosy within their educational system during the colonial era, which increased the stigmatization of leprosy and its sufferers. The Madurese leprosy folktale, Ragapadmi, was used as one of several teaching materials during the Dutch occupation to teach the natives about the dangers of—and disgust for—leprosy.



Figure 4.2. Traditional boat to Gili Mandangin, the only way to access the island.

Alternative rationality

"If it is not in Gili Mandangin, let's say you were teaching in Bangkalan, and you see white marks on your student's skin, would you ask your student to get an examination?" I asked Andhika during our travel back to Sampang. He laughed, and answered, "No, that must be *panu* (skin fungus)." I laughed, realizing that disease detection might depend on the region. It is a part of geo-medicine discussion, I believe, when people choose to aware of a certain disease when they live on one area and of another disease when they move to another area. But I will not discuss further about this in this thesis.

Teachers in Gili Mandangin were asked to be aware of white marks on their students' skin, as it is the first sign of leprosy. The first action they are told to do is ask the students suspected of leprosy to stand under the sunlight. "I am not really sure why they are asked to stand under the sunlight. After that, we are supposed to list the student's name and instruct

them to go to the hospital regularly," said Andhika. To visit the hospital regularly means once in a month since accessing health facilities is not easy for Gili Mandangin people. At the time I was there, there was no *Puskesmas* (Public Health Service) on the small yet densely populated island. There are more than 22,000 people living on the island according to *Daftar Pemilih Tetap* (election voters data, focusing only on adult people who have the right to vote), according to the chief of the village.

The western area of Madura which covers Bangkalan and Sampang regencies, according to *Peraturan Presiden* (Presidential Regulation) number 131/2015, are categorized as underdeveloped regions in Indonesia. Thus, Gili Mandangin is not only underdeveloped, it is also isolated (*daerah terasing*). Access to information, transportation and health service remains very difficult for people living on the island. These conditions encourage the transmission of the traditional perceptions of leprosy among generations. Yet, it is very surprising that their perception of leprosy is positive among the Gili Mandangin people and that leprosy sufferers are not seen as contemptible or disgusting.

Related to the different perceptions of leprosy held by the Madurese who lived on the isolated island of Gili Mandangin and who were exposed to modern education system, I noted during my fieldwork that some of my respondents create a gap between me as a researcher and their position as informants. For my Madurese respondents, regardless of my identity of origin as a Madurese, they felt I had lost my traditional roots due to my education. Moja, for example, started his explanation by saying, "you must find it hard to accept what I will say to you because you think rationally," while Pak Ajjih argued that I misconceived the leprosy folktale Ragapadmi as well as other anak sekolahan (school boys). In this way, (modern secular) education appears as the distinguishing factor between me and my Madurese respondents. If the European knowledge which is gained through scientific

research procedures is regarded as *rationality*, then how can we define the non-Europeanized forms of knowledge that are inherited over generations and have become the native's epistemology toward everything around them?

History has it that living together with leprosy sufferers was a common practice among the natives in the Dutch East Indies and in Hawaii until at least the beginning of the 20th century, when leprosaria were institutionalized.⁵⁰ This practice was also found by Francisco Alcina among the Visayans during his stay in 1600s,

I also observed that the husband was totally $cascado^{51}$ and the wife not at all; in others, just the opposite, I noticed. Thus, having three or four or more children, some of these were totally unaffected while others completely cascados. This is worth bearing in mind that these people living as they live, and sleeping as they sleep, all grouped together; if this does not take place, then a sister lends her blanket to her brother and the mother to her children, it can be seen that some are not infected. Others, are easily infected. Hence, we may conclude that it lies in the nature of one's disposition. (see Alcina, 2002: 485)

Interestingly, the same practice was not known among the Abrahamic-believers from the Middle East and Europe. In the Bible, there is a story where Jesus cured 10 lepers so they could go back to their society. It means that leprosy sufferers were isolated among the society except if they were cured. In Islam, there is one *hadith* cited by Bukhori, "run away from people with *judham* (leprosy) like you run away from a starving lion." In Leviticus, the well-known *tzaraath*, mentioned above, implicates isolation and condemnation towards its sufferers. The same belief also appears within Hindu believers in India where leprosy was called *kushta*, which simply means dirty or ugly. So, the practice of living together with

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⁵⁰ For The Dutch East Indies, see Van Dort in his interview with *Haagsche Courant* published on November 27, 1897, and for Hawaii, see historical report from Ron Amundson & Akira Ruddle-Miyamoto, *A Wholesome Horror: The Stigmas of Leprosy in 19th century Hawaii*, 2010.

⁵¹ Suffering from leprosy.

⁵² *Hadith* is a collection of Mohammed's words or deeds as retold by his fellows to their students. Regarding this *hadist* about leprosy, Gus Hilmi, an Islamic medical practitioner in East Java, during interview on August 5, 2017, said that 'run away' should not be interpreted as avoiding or ignoring the leprosy sufferers, but finding a way to cure the sufferers so everyone could run away from the disease.

leprosy sufferers in some parts of Indonesia, the Philippines and Hawaii is based on a very ancient perspective on leprosy, possibly believed by the Pagan-Austronesians during their migration out of Taiwan as discussed in the beginning of the Chapter Two in this study.

The perception of leprosy held by people in Gili Mandangin, I assume, is deeply rooted to the ancient belief, which proposes material things as the origin of everything. This belief can be traced from the Austronesians' myths about human creation. The Dayaks believe that the first man was born from two birds that created human from trees, rocks, and soil. In Sarawak, the natives tell about a story of Battara who created a human from mud. A different story comes from the Visayans, who believe that the first human was created from a bamboo tree. These Austronesian origin myths show the direct connection between creation stories and the visible materials around them.

However, it is important to note that the Gili Mandangin people, almost all, are loyal Muslim believers, seen from their daily outfits in which all women wear veils and most of the men wear *sarong* and *kopiah*. The way they treated the Ragapadmi folktale is also very Islamic: Islamic graves built inside a mosque, Bangsacara's status as the student of a highly regarded Islamic scholar in Java, the presence of Kyai Gemma who found Bangsacara and Ragapadmi corpses—as well as the one who made an oath not to eat any mackerels and *kue cucur* that becomes the history of leprosy in Gili Mandangin. Their rationality, I assume, is not a pure Pagan rationality. It is an alternative, a combination of religious values and an 'autochthonous' rationality inherited from the Pagan-Austronesians.

While the Madurese who live on Gili Mandangin seem to feel uneasy with the exposure to scientific rationality, it does not mean that they have no ideas about leprosy. Living remotely due to leprosy stigmas and left-behind status, leprosy in Gili Mandangin is assigned to one historical event experienced by their ancestors. Leprosy is rationalized as an

oath of their ancestors, and the causative agents are manifested in form of mackerel and a traditional snack. There is a general perception among the Madurese that a disease might be transmitted if the sufferer has *settong dara tonggal daging* (one blood same flesh) with former sufferers or someone in the past who was connected to the historical account of the disease. For example, the Madurese believe that a diabetic father will transmit the disease to his daughter. In Gili Mandangin, leprosy is believed to afflict only the male descents of the island's founder. When I asked them about the island's founder, there are two opinions that came to me. The first, the founders were Bangsacara and Ragapadmi, while the second opinion argues that the island was found by an Arab, named Habib Muhammad, who rode a coconut leaf from Saudi Arabia to Gili Mandangin.

I also noted that the Madurese do not have exact terminologies for leprosy. If the words *kusta* and *lepra* are adapted in the Indonesian language to mention leprosy, the Madurese leprosy terms are more about describing the characteristics of the disease. *Sake' juba'* means ugly sickness and is used to describe the characteristic of leprosy which makes the sufferer's face imperfect, or *dhaging bucco'* means rotten flesh which describes physical mutilation on any parts of the sufferer's body. Another word, *tetthel*, possibly comes from the Javanese word *tetelan* means small parts, also used by the Madurese to describe finger mutilation on the sufferer. We cannot ignore the word *sompa'an* (oath) used by the Mandangin which signifies the closeness of the disease to their historical events. More than that, the Madurese are also able to distinguish leprosy from other diseases that also cause physical mutilation like *Diabetes*. A local explained the difference between *daging bucco'* (leprosy) and *daging manes* (sweet flesh, used to refer to diabetes) and that the corruption on

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⁵³ This perception is also noted by R.E. Jordaan during his research in eastern Madura, see: *Folk Medicine in Madura (Indonesia)*, 1985: 201.

daging bucco' occurs at the joint of the middle phalanx, while daging manes occurs at the center of the middle phalanx (see Figure 4.4).

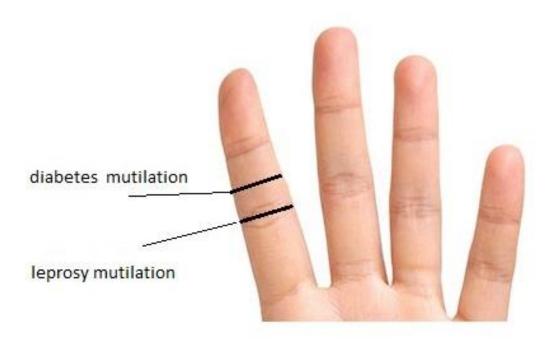


Figure 4.4. Difference between diabetes and leprosy mutilation according to the Madurese

Conclusion

How the Madurese in Gili Mandangin perceive leprosy seems very different from how science describes the disease. Science is a process of answering an infinite chain of questions, which emerged after one question was answered or, in other words, science is still in the making. Yet, older knowledges which offer an instant answer also seem contradictory to religious dogmas about the unseen and non-debatable as the cause of everything. This abstract element could be considered wrong either by the scientists or religious missionaries and scholars. However, it exists and is considered correct within the rationality of the indigenous people. In this way, these older knowledges appear as what I am calling alternative rationality.

On the issue of leprosy, scientific rationality and alternative rationality both present a complementary mutual opportunity to tackle the problem of leprosy's silent transmission. Science has confirmed that leprosy is contagious and is caused by a kind of bacteria, thus medical treatments and preventive vaccines have been found to tame the disease. However, the history has it that when science was taught improperly, the negative stigma of leprosy appeared as the result, and science has nothing to do with it. On the other hand, alternative rationality with its negation of the visible and legible process remains insightful for understanding the ways of thinking in older societies. What I learned from people on Gili Mandangin was that by understanding that leprosy is closely related to their ancestor's oath, leprosy sufferers are not seen as contemptible and irrelevant.

Even though the people on Gili Mandangin use an alternative rationality when they think about leprosy, the presence of leprosy sufferers among people in Gili Mandangin should not be ignored. As long as the causative agent exists in the area, leprosy will still be transmitted. Healthcare and education about hygiene is also urgently needed on this populous island, as well as in its neighboring islands of Madura, Java and Bali. Access to medical treatment is surely the vital point for leprosy eradication, but the correct explanation of the origin of leprosy is also important for combating the stigma and also to understand the different rationalities people can have about leprosy. When the stigma vanishes, society will be more supportive to the rehabilitation process of leprosy-affected people. When the rehabilitation process runs smoothly, the eradication of leprosy will no longer be beyond reach.

Chapter V

Epilogue

In addition to the historiography of leprosy transmission in Madura, this study also presents two different perspectives related to leprosy. The first perspective, the one that I mentioned as an *alternative rationality*, is ancient yet still recognized in certain areas. This perspective ignores solid reasoning and promotes either black magic or divine intervention as the *prima causa* of leprosy transmission. The positive side of this alternative rationality is that it offers a wider space for leprosy sufferers to stay within their societies and not to lose their rights as human beings. The second perspective is more familiar in this modern era and is rationalized by scientific reasoning. *Mycobacterium leprae* is confirmed as the causative agent and it is easily transmitted through intensive interaction. However, history has it that science could not help to humanize the leprosy sufferers. After announcing that leprosy was contagious, the Dutch—and many other colonizers in the world—implemented compulsory segregation policies. These policies were followed by improper health propaganda about leprosy. As a result, many leprosy sufferers in many societies are still treated like the living-dead even now.

Meanwhile, the conception of alternative rationality itself is still far from distinct. The area of study of this thesis, which is only a small region of Madura and Gili Mandangin, is still insufficient to support the acceptance of the idea of an alternative rationality. During my readings, I also found a number of indigenous conceptions of leprosy that I presume are a part of alternative rationality. In Aceh, 1914-1938, for example, many leprous fighters became lone-wolves who terrorized Dutch officers because the indigenous concept of leprosy collided with religious doctrines. From Gili Mandangin, we know the story of Ragapadmi, a

folktale about a leper princess with a strong Islamic nuance. In Bali, as presented by Vicky Baum in *Tale of Bali*, indigenous perceptions were influenced by the Hindu beliefs of the natives.

Until the wrapping up of this study, I presumed that at least four kinds of rationalities about leprosy were widely held in what now called the Indonesian archipelago. The first is autothocthonous rationality, as portrayed in a number of leprosy folktales spread from Borneo to Sulawesi, Java and Madura and possibly small islands around them. The second is religious rationality that I suspect to have developed in the western and central part of Indonesia passed by international merchants from Middle East and India during the ancient maritime trade. The third, scientific rationality, was brought by the Dutch through their efforts to understand the disease as well as through the leprosaria policy. While the fourth, alternative rationality, is the combination of two, or maybe three, of the afore-mentioned rationalities which still exist in recent times. Surely, a deeper historiography involving a wider area of study is needed to confirm my presumption. In the end, I hope that this study of Ragapadmi and its publication might make a contribution towards the development of area studies of Indonesia as well as the field of history and the ethnography of medicine.

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