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To cite this article: Dimas Iqbal Romadhon (2020): A critical comparative ethnographic study of courtesy stigma in two leprosy-impacted communities in Indonesia, Global Public Health, DOI: [10.1080/17441692.2020.1718734](https://doi.org/10.1080/17441692.2020.1718734)

To link to this article: <https://doi.org/10.1080/17441692.2020.1718734>



Published online: 23 Jan 2020.



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A critical comparative ethnographic study of courtesy stigma in two leprosy-impacted communities in Indonesia

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ABSTRACT

Leprosy stigma is more neglected than the disease itself since global interventions towards leprosy are focused on the medicalisation of individual-sufferers and statistical counting of documented cases and less prioritising the impact of leprosy stigma towards society. This paper examines the impact of courtesy stigma on society through comparative ethnographic method conducted in two sites in East Java Province, Indonesia. Investigation in the first site, Mandangin Island, found that the island suffers underdevelopment of public facilities such as clinics and clean water and migration and medical knowledge bottlenecks. In the second site, Sumberglagah village, leprosy patients and the community they live with are also socially separated from the locals and they are engaged in controversial businesses exploiting the public fear of leprosy. This study finds that leprosy stigma in two leprosy-impacted communities in East Java, Indonesia, does not only isolate individuals but also a whole community from a bigger society regardless of whether *all* of the community members have leprosy. This study also detects problems related to leprosy education within the two impacted communities. It is suggested that efforts to address the problems require holistic approaches and commitments from various actors in the area in complement to existing global health missions.

ARTICLE HISTORY

Received 27 October 2019

Accepted 13 January 2020

KEYWORDS

Leprosy; ethnography; courtesy stigma; community; Indonesia

Introduction

The World Health Organization (WHO)'s claim on the global eradication of leprosy in 2000 sparks debates among experts and academicians who mainly question the prevalence parameter, 1:10,000 new case detection rate (NCDR), used to support the claim. Many scholars argue that NCDR statistical model is an irrelevant measurement tool since it risks missing cases and undertreating patients and real-life evidence only for policymaking purposes, as well as it is an unethical practice for policymaking since NCDR ignores evidence-based causal relationship. (Declercq, 2001; Lockwood, 2002; Meima, Richardus, & Habbema, 2004; Penna, Temporão, Grossi, & Penna, 2011) The statistical approach to measuring leprosy case detection, unfortunately, is also prone to miscalculation. The word 'new' in NCDR indicates that it will not include leprosy patients from previous years who, for many reasons, stop accessing medical treatment and decide to keep the disease with them. As how Geoff Prescott highlights in his highly provoking article *Leprosy: The Search for the Missing Millions* (2017), the data gathering method of NCDR, which depends heavily on its field investigators, seems vulnerable to overlook leprosy patients who live in hiding, misdiagnosed, or live in a region far beyond the reach of the investigators.

From the social science perspective, we could also criticise the WHO's prevalence parameter as lacking the social dimension of the disease, and instead, as we can also see from 2018 WHO's Official Guidelines on Leprosy Diagnosis, Treatment, and Prevention, giving more emphasis on medical intervention. It is contrary to the perspectives of some leprosy scholars who argue that attention to leprosy stigma should weigh the same as the attention to measure its prevalence as stigma might affect the lives of stigmatised patients and their families as well as their communities. (Peters, Zweekhorst, van Brakel, Bunders, & Irwanto, 2016; Weiss, 2008) By counting on the individuals, the measurement fails to address the problem of social stigma, one crucial thing which directly influences sufferers from getting necessary treatments. Those who work with leprosy stigma from any perspective surely understand that the pain of being socially excluded is more severe than the pain of the disease. (For example, Diokno, 2016; Ibikunle & Nwokeji, 2017; Peters, Dadun, & Lusli, 2013) This situation bears a critical question on the WHO's claim: what is the meaning of leprosy eradication without stigma eradication?

Erving Goffman (1963, p. 30) has already introduced us to a situation where stigma finds its way to disqualify not only individuals with particular character but also the whole community living together with the individuals, 'the problems faced by stigmatized persons spread out in waves of diminishing intensity among those they come in contact with'. A number of scholars examine this situation, later mentioned as courtesy stigma or stigma-by-association, in its association with sex workers, people affected by HIV AIDS patients, people with mental disorders, and people with other stigmatised social characteristics, and how the stigma directly impacts their family's everyday lives. (Khamis, 2007; Kinnear, Link, Ballan, & Fischbach, 2016; Phillips, Benoit, Hallgrimsdottir, & Vallance, 2012; Siegel, Meunier, & Lekas, 2018) Another line of scholars also generates a causal association between courtesy stigma and territorial space to understand how certain stigma advances marginality and later results in health inequalities in a certain region where a courtesy-stigmatised community lives in. (Keene & Padilla, 2010; Pearce, 2012; Wacquant, 2007)

This paper is intended to extend scholarly discussions related to the courtesy stigma. While there is a general belief that leprosy stigma works between individuals and their society, most of the existing scholarships regarding disease-stigma investigates the impact of stigma in a more limited way, focusing on the individuals and their close families. The cases that I present in this study show that leprosy stigma does not only occur in the individual-society level, but it also occurs in the community-community level. However, we still know very little about how severe leprosy stigma can impact communities. What this paper also does is to shed our intellectual attention to people living surrounding stigmatised group of people who are not directly related to the group members. I introduce a term *leprosy-impacted community* to mention a group of people living together, sometimes separately, with leprosy sufferers, building one connected neighbourhood, which covers social, cultural, economic, and political aspects of the community.

Method: Critical comparative ethnography

Critical ethnographers bring within their practice some political aims to 'speak to their audiences on behalf of subjects as a means of empowering them by giving more authority to the subjects' voices.' (Thomas, 2011, p. 4). This definition suggests the employability of the method of ethnography, which utilises a holistic approach to study specific phenomena in one specific setting, to bring up voices from the field to challenge the current social framework and also to influence the process of policy decision. Unfortunately, the ethnographic method, due to its specific setting, is often criticised for the size of the population or study area it is working on and the representativeness of the study. To provide a larger area of study and variety of research findings, I decided to use multiple sites for a comparative ethnography to provide notes from fieldwork to influence policies that can also be called Critical Comparative Ethnography. Adding a comparative approach to ethnographic research will tackle critics towards ethnography on the issues of population or setting, the

translatability of findings when applied to different contexts, and the representability of the case. (Simmons & Smith, 2019, p. 342). Comparative ethnography will also help researchers to identify the phenomenon better, highlight contrasts in practices, promote interdisciplinary collaboration, and also enhance accessibility of the study for scholars who are not familiar with the method.

This paper is built upon eight months of comparative ethnographic fieldwork during 2017–2018 focused mainly in two different sites in Indonesia, a country with the third highest number of documented leprosy cases according to the WHO's 2015 report. The two areas in Indonesia are chosen with specific consideration on the level of exposure towards medical intervention. This issue of medical intervention exposure matters in this study since it influences the way people are being exposed to a specific leprosy perspective, which can be based on popular/local beliefs, biomedical information, lived experience, or a combination of all three. The findings of this research contribute to a better understanding of how leprosy stigma impacts social lives.

The first area chosen as the ethnographic site is Mandangin, a tiny island located between the island of Java, Indonesia's main island, and a smaller island than Madura. The island was underdeveloped, hard to reach, and heavily associated by local people with leprosy. There is a local folktale telling about a local princess named Ragapadmi who suffered from leprosy and isolated to the island until her death. As rumoured by people around the island, Mandangin was a designated place to isolate leprosy sufferers in the colonial time. It is not difficult to find any internet sources confirming this stigma. However, library investigations conducted in Jakarta, Surabaya, and Leiden failed to find any government documents confirming the official use of the island as leprosarium in the past time. Until now, the rumour of leprosy in Mandangin has surpassed its coastal beauty and the kindness of its people. The second chosen area is Sumberglagah village, located in the administrative area of Mojokerto. Sumberglagah is known for its leprosy hospital, Sumberglagah Leprosy Hospital, which becomes the centre of leprosy treatment in the eastern part of Indonesia. In conjunction with the commemoration of World Leprosy Day 2015, Mr. Yohei Sasakawa, the WHO Goodwill Ambassador for Leprosy Elimination, visited the two areas, proving that significant attention should be given to the areas. Mr. Sasakawa is prominently recognised for global activism on leprosy eradication through his Sasakawa Foundation and also the campaign leader in promoting leprosy and social problems associated with the disease as human rights issues rather than merely global health issues. (Aerts, 2019). During the visit, Mr. Sasakawa could make a meeting with leprosy sufferers in Sumberglagah and even washed their legs, while, for some reason, he did not travel across the strait from Madura to Mandangin and only presented the local myth of leprosy princess by the government officials instead.

My primary data collection methods are unstructured interviews and participant observation. I focused my research participants on people living together with leprosy sufferers in the mentioned regions and made little data collecting interactions with the sufferers and their families. Unstructured interviews were done in various public spaces, such as mosques, food stalls, markets, boats, and so on, with a targeted intention to build a narrative of everyday life from people living together in the same neighbourhood with leprosy sufferers. Due to the nature of the unstructured interview method and the public spaces where the interviews were conducted, it is hard to number how many people I interviewed and communicated with. In estimation, I talked with around 50 people from the two sites in various interview settings. There were several times when I interviewed one interlocutor some people came in the middle of the interview and joined our conversation, and then I decided to continue the conversation in the form of informal, unfocused group discussions. Participant observation was conducted through various activities, including joining social gatherings, crossing the strait together with the locals in Mandangin, and making visits to the nearby traditional market in Sumberglagah. I also did library research on official documents and daily newspapers related to social dynamics in the two regions. It is also important to note that data collection in Mandangin is a part of a different project to document the leprosy folktale of Ragapadmi (Figure 1).



Figure 1. The location of the two ethnographic sites in Indonesian map.

Findings

Ethnography in Mandangin

I started my fieldwork in Mandangin from Madura, the only gateway to visit the island. When I interviewed some local people in Madura, I was directed by their information which associated Mandangin with leprosy. When I followed up the information with a question on why they believe Mandangin Island is a leprosy island (*pulau kusta*), they referred to one popular local folktale as how one interviewee, Nur, answered,

There is a story about Ragapadmi, a princess from the Pacangan kingdom in Tragah, who was isolated to Mandangin because of suffering from leprosy. She died there and was buried on the island, too, side by side with her husband.

Library research that I conducted on Ragapadmi found that the local folktale has been documented in at least ten publications from 1900 to 1990, making this folktale as the most popular folktale from the region. The mythical connection between leprosy, Mandangin, and Ragapadmi folktale is also mentioned by Syaifullah Yusuf, the vice governor of East Java, in his 2015 interview responding the Indonesian Ministry of Health's report on leprosy.

Mandangin Island is a very tiny island with only 1.67 square kilometres yet inhabited by 19,798 people. (BPS Kabupaten Sampang, 2019) From that small size, only a three-fourth of the island that can be used for housing while the other half is restricted from the locals as it is owned by a multinational oil company, Santos. The island is very dense and suffering from over-population and lack of public facilities such as clinics (at least until 2019 when the first health service centre was officially opened by the local government of Sampang), traditional markets, or clean water sources. However, I noticed that inter-island migration from or to Mandangin is very rare. When I asked Mandangin people why they decided to live in that situation, they told me a past glorious era of the island, which made no one wanted to leave Mandangin. 'There were so many fish around the island, and fishing here was far easier than in Madura', said one of my Mandangin informants. However, when I asked my Madura informants, they said that they would rather stay away, or even refuse if someone from Mandangin moves permanently to their villages.

Migration bottleneck or 'stuckness' was the most visible impact of leprosy in Mandangin. Every morning, not less than 50 traditional motorboats served Mandangin people's mobility. They went across the strait to Madura to buy daily needs from markets, consisting of tofu, rice, sugar, snacks,

clean mineral water in bottles, even grass for feeding goats. Around one o'clock in the afternoon, the same people would take available boats to go back to Mandangin with their daily needs in hand. Sometimes, they also carried illegal motorcycles and cars from Madura on the boat and never felt afraid of doing that since there were no police officers on Mandangin island. The boat took at least two hours for a one-way route from Mandangin to Madura or vice versa, often took a longer time than that. I remember one gloomy evening when my boat was stranded, and it needed six hours of three men's efforts to put the boat back on the track. One of the boat operators told me that he knew all Mandangin people who took his boat, simply because nobody left the island permanently and he could even recognise if someone were missing in his afternoon route back to Mandangin (Figure 2).

Mandangin is also very remote in the context of public facilities. There was no market in Mandangin, even though almost all of the inhabitants were fishermen. They would take their caught fish to nearby fish markets in Madura where many fish traders waited for them every morning for fresh produce. It seemed that no one of the fish traders ever thought or had a plan to visit Mandangin daily if the island had one fish market so that Mandangin fishers should make themselves active sellers by travelling to Madura to sell fish caught in the water area near Mandangin. There were nine elementary schools, one junior high school, and one senior high school on the island. Most of the teachers in these schools were from other regions outside Mandangin and chose to live in Madura rather than in Mandangin. As a consequence, they needed to cross the strait in the morning and evening, losing an average of precious four hours daily for return travel.

I interviewed one of the Mandangin teachers who had been teaching in Mandangin for 14 years, and during his long dedication to Mandangin education, he never stayed even a single night on the island. He lived at a house near the small port in Madura to allow him to easily reach the port to catch a boat to Mandangin. He did not give an exact reason why he decided not to live in Mandangin, but I think whatever the reason was it has something to do with leprosy issues in Mandangin since he loved to tell me a joke about new teachers who were driven by their fear of leprosy in Mandangin.

I used to make a joke on them (new teachers). There was a time when one of the student's parents came and brought *rujak* (local fruit salad) for all the teachers here. I knew that those new teachers were hungry and wanted to eat the *rujak*. But then I told them that the *rujak* seller's fingers were like this (at this point in his story, he was bending his fingers imitating leprosy sufferer's mutilated fingers). Then they refused to eat the *rujak*. But other teachers who lived in 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.

There was also a leprosy information bottleneck in Mandangin. I interviewed Ivan, a physician and also a professor on public health from a notable public university in Java. He once organised a free health clinic event in Mandangin in which leprosy was among many disease programmes in the event. Ivan told me that he was made aware of the leprosy problem before going to the island.



Figure 2. Overloaded ferryboat to Mandangin.

However, as he remembered, no one came to the leprosy clinic. He also told me that during his programme in Mandangin, he did not encounter any leprosy sufferers. This was different from my experience during my stay in Mandangin when I did meet several leprosy sufferers, not in a significant number, interacted with other people, and did their daily activities normally as if they were not suffering from leprosy. I remember I was in the queue for clean water together with an old woman whose fingers were mutilated entirely and her face showed the symptoms of leprosy.

To confirm Ivan's information, I asked locals in Mandangin whether they are familiar with leprosy (I used Indonesian term, *kusta* and *lepra* interchangeably). One man that I asked responded firmly, 'there is no leprosy in Mandangin'. He said he had lived for more than 50 years in Mandangin and never heard of any Mandangin people having leprosy or people isolated to the island due to leprosy. He even believed, as also supported by another man during our conversation on a boat to Mandangin, that people in Madura listened to the wrong version of Ragapadmi story. 'She was not isolated to Mandangin; she was cured by her husband while they were still in Madura. She only went to Mandangin to accompany her husband, only a short time before she and her husband died'. Another informant, a teacher, explained that people in Mandangin had a different perception on the physical situation that I mentioned as leprosy,

People mentioned leprosy as *sompaan*. People here have a taboo; they are not allowed to eat *kue cucur* (traditional fried cake) and *tengiri* (a kind of fish from mackerel species). They believe that their ancestors were helped by a group of *tengiri* thus, the ancestors vowed not to eat *tengiri*, and their descendants should not too. If one of their descendants breaks the taboo, he will suddenly get a skin disease. Men are more susceptible to break the rule and get *sompaan* rather than women because men work as a fisherman.

Based on the information from my Mandangin interlocutors above, the case where no one came to the free clinic could be connected to three possible reasons: fear of being associated with the widely stigmatised leprosy (*kusta* or *lepra*) disease, inability to detect and distinguish symptoms of leprosy from other physical impairments or disabilities, and disagreement between local and medical perspectives related to leprosy. These three possible reasons signify problems related to leprosy education.

Ethnography in Sumberglagah

Around 50 metres to the left of Sumberglagah leprosy hospital, there is a dense neighbourhood. Near the entrance of the neighbourhood, there is a metal board stating that the land is owned by the government of East Java Province. There were certain questions that arose for me because of some of the irregularities with this neighbourhood. What kind of neighbourhood located on the government-owned land? Why is the neighbourhood denser compared to the surrounding neighbourhoods?

'We call the neighbourhood *kampung* (sub-village) *Berdikari*', said one of Sumberglagah village officials. *Berdikari*, an abbreviation of *berdiri di kaki sendiri* (standing upon our own feet), is a famous quote from the Indonesian first president, Soekarno, during the political turmoil of Cold War in order to urge Indonesian people to be autonomous and independent from imported stuffs, aids, and other influences from both political axis the United States and the Soviet Union.

In the old days, around 150 leprosy patients from the hospital were sheltered in the neighbourhood. They could not go back to their original places because they had leprosy. Then the government decided to make a designated neighbourhood for them and provided them with monthly basic care package.

This package basically includes rice, frying oil (*minyak tanah*), sugar, and other basic needs. I assume that those government supports were intended to make these leprosy patients be able to stand upon their own feet.

That was several decades ago. During my stay, there were only around 50 people with apparent signs of leprosy living in the neighbourhood, but the number of residents was more than that. Leprosy sufferers living in the neighbourhood started their new life, had families, and then extended families, and now the population of healthy people living in the neighbourhood exceeds the number

of leprosy patients. But the government permission of land use, as well as the monthly ransoms, are still given to Berdikari residents until nowadays.

If the term *Berdikari* has a deep historical meaning for most Indonesians, this term denotes different meanings for the locals in Sumberglagah. It marks differentiation not only between sick people and healthy people but also between newcomers and the locals. 'They are not from around here; many of them are from Madura, Bali, and Kalimantan, and they cannot go back home', said a local informant. To make a clear distinction, the locals mentioned themselves as *orang sini* (local people). From my observation, *orang sini* and *orang Berdikari* create a strange mutual symbiosis: unwanted yet significantly helpful. Many Berdikari people used to sell their monthly ransoms at a lower price than the market. 'When selling stuff', said one food stall owner, 'they are *memaksa* (forceful). I used to buy their stuff, besides the price is *miring* (far cheaper than in the market), I want them to leave the shop soon'.

Different from people in Mandangin, geographic and facilities barriers are not problems for Berdikari people. Even public streets heading to their neighbourhood are better constructed compared to streets in the neighbouring village. As the village official revealed, 'the presence of leprosy patients in the village is like an asset for us. Every time I send construction proposals to the government, they never reject it since they know it is for leprosy patients'. As a result, Berdikari people have very high mobility. It is easy to meet one of the leprosy patients from Berdikari begging for money in streets ten to fifteen miles away from the village.

Economic activity involving Berdikari people is very active. Not only through selling subsidiary stuff or begging in the streets, Berdikari leprosy patients also involve actively in debt-collecting business in the town. This business is commanded by some coordinators living in Sumberglagah village, not necessarily Berdikari people, and they accept debt-collecting orders from anywhere in Mojokerto Regency. After accepting an order, a coordinator will take around eight to ten of Berdikari leprosy patients with him using an open cabin pick-up truck to a target's house. Not only leprosy sufferers but sometimes healthy residents of Berdikari also take part in the activity if needed. At the target's house, the Berdikari debt-collectors do nothing, but their presence is very effective in making the house owner feel terrorised. Sometimes the debt-collectors also urinate on the house or knock on the door to get attention. At noon, the coordinator will come again bringing packets of lunch for them. In the evening, the pick-up truck returns to carry them to their village.

The stigma of leprosy in Sumberglagah has brought a situation that Mike Davis (1998) called 'ecology of fear' into the city. The idea that they could get leprosy comes into the mind of people when hearing the word Sumberglagah mentioned. Yet, why does the presence of leprosy hospital in the region not help diminish the stigma of leprosy?

I notice that the presence of the leprosy hospital in the village has transformed the locals' medical perspective on leprosy. Many locals confidently explained that leprosy would no longer be contagious if it had been treated, the same medical narrative distributed by the hospital. But when I asked them how they knew the information, they gave me different sources which all of the sources were informal, or through social networks and not directly from medical authorities. A woman told me that she knew it from her friend who worked as a parking-man at the hospital. Some others just said that they heard that too but could not remember how and from whom they heard that information.

However, as to how I learned from my fieldwork in Sumberglagah, the distribution of medical knowledge and the presence of medical intervention centre for leprosy in the region do not help people from the impact of leprosy stigma. Moreover, since the geographical situation does not hinder the activity and mobility of the stigmatised people, they appear to be a terror for other communities. As a consequence, leprosy stigma is exploited for political and economic purposes.

Conclusion

Ethnographic fieldwork from these two areas demonstrates the presence of communities that are profoundly impacted by leprosy stigma despite the fact that not all of the community members

have or had leprosy. Division, a central theme that has been generated by many social scientists of leprosy in previous times, obviously exists, but it happens in community-level rather than in individual level. People in Mandangin are separated and even socially isolated from their Madurese neighbours even though administratively the island belongs to Sampang, one of four regencies in Madura. Geographic location helps the formation of the social division of both communities. People in Sumberglagah do not have any geographic barriers; however, the social division appears in form of state-supported neighbourhood for leprosy sufferers named Berdikari which is positioned as an exclusive village within village.

Comparing social division in the two sites, I noticed that geographical difference creates a different kind of social problem related to leprosy stigma. In Mandangin, leprosy stigma is addressed to the island and people in Madura will only worry about leprosy if they travel to Mandangin or if they have someone from Mandangin stay around them. The natural barrier and the lack of transportation create a stuckness of migration and mobility for Mandangin people but give comfort for Madurese people. Differently, in Sumberglagah, Berdikari people have high mobility and involve actively in economic activities. They comfortably wander the town and bring terror to people who already feel fear as the result of leprosy stigma.

Another comparable feature of the two sites is the presence of medical intervention towards leprosy. It is surprising for me that the isolated community of Mandangin could develop social solidarity within their community that respects the existence of leprosy sufferers on the island in the same social position as other community members. Things are in contradiction in Sumberglagah where a leprosy hospital is present and in operation, but the fear of leprosy is also present in the village. Considering this finding, I do not want to make an argument that social solidarity is the result of the absence of medical intervention, or that the presence of medical intervention triggers the stigma of leprosy; however, I would argue that scientific intervention does not necessarily promote solidarity within leprosy-impacted communities.

It is important to give specific boundaries for leprosy-impacted communities. I would suggest that any communities could be categorised as impacted by leprosy if their social structure is influenced by leprosy stigma. Either community who are stigmatising or stigmatised, who are isolating or isolated, could be categorised as leprosy impacted communities. This term is specifically addressing communities' vulnerability towards problems caused by leprosy stigma. With this definition, we can surely estimate how large the size of the so-called leprosy-impacted community is. Earlier studies from James Staples (2007) on begging activities and from Ronald Barrett (2005) on self-neglect behaviour among leprosy patients in India that are quite identical to what I found in Berdikari and Mandangin confirm the shared characteristics of leprosy-impacted communities.

As we could also imagine the vulnerability of our communities when being exposed to leprosy stigma, it gives us a distinct task to do regarding community education. Leprosy education is the central programme that we need to improve by integrating medical information and cultural perspectives to avoid people's hesitance to participate in the programme. Public forums involving medical professionals and local community figures are also needed to address existing social problems, such as debt-collecting, begging, and migration stuckness. Reconciliation is undoubtedly needed for communities in which structures are already impacted; while for communities that have not exposed yet to leprosy problems, activities related to social capacity and solidarity building can be prescribed for prevention. It is also expected from the Sumberglagah Leprosy Hospital to take more involvement in the prescribed programmes in both Sumberglagah village and the Mandangin island which are located under its service area. In specific to Mandangin Island, improving public infrastructure such as health service, public market, and clean water is also an essential action to take by involving the multinational company working in the area through corporate social responsibility. In sum, since leprosy does not only impact individuals but the whole community living in the neighbourhood, efforts to address the problems require holistic approaches and commitments from various actors in the area in complement to existing global health missions.

Acknowledgments

I would like to express my highest appreciation to all interlocutors in Mandangin and Sumberglagah who kindly shared their information and experience; to the family of Rachmad Salim and the family of Muji Rahayu who hosted me during my fieldworks; to Ayus Andika and Ahmad Dwi Muntaha who accompanied me during my fieldwork and helped me get along with the locals; and to Ivan Rahmatullah and Zulham Mubarak who provided me with valuable information about the sites. I would also like to thank Laurie Sears, Christina Sunardi, Peter Lape, Celia Lowe, Janelle Taylor, Danny Hoffman, James Pfeiffer, and anonymous reviewer from the Global Public Health journal whose attentions and suggestions have improved this article from its very rough idea to this final version.

Disclosure statement

No potential conflict of interest was reported by the author.

Funding

The author received financial support from the Southeast Asia Center at the University of Washington through Keyes Graduate Travel Award 2017 and 2018 and The Christen J. Grorud Memorial Fellowship 2017. Local supports during the fieldwork are provided by Yayasan Karyaalekha Basa and Universitas Islam Raden Rahmat Malang. The funders and supporters had no role in study design, data collection, and analysis, decision to publish, or preparation of the manuscript.

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