

Leprosy, impurity, and stigma in Vietnam

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Abstract

This Position Piece examines the nature of Vietnamese folk constructions of leprosy through Mary Douglas's (1969) and Victor Turner's (1967) works. Investigating Vietnamese explanations for the origins of leprosy and its channels of transmissions, symptoms, and consequences, I argue that these accounts are rooted in narratives of transition, transgression, the crossing of boundaries, and categorical confusion of various kinds. I argue that these deeply embedded perceptions of leprosy help to explain the existence of persistent stigma against leprosy in Vietnam, despite highly effective drug treatments and extensive state awareness programmes.

Keywords

Leprosy, Vietnam, Pollution, Mary Douglas, Victor Turner

Introduction

In the early stages of my doctoral fieldwork on living with leprosy in Vietnam, a motorcycle taxi driver would take me to the Quy Hòa leprosy village every day.^{1,2} I was staying in downtown Quy Nhơn city, seven kilometres away, while waiting for research permission and accommodation in Quy Hòa to be arranged. When I first asked my driver to take me to the leprosy village, I also asked how he felt about going there. He confidently responded that he had heard about leprosy a lot through TV and newspapers, so he did not feel afraid. However, as soon as the driver learnt about my planned interaction in close proximity with the people in the leprosy village, he expressed serious concern. He gave me detailed advice about what I should not do when interacting with Quy Hòa villagers—for example, I should not sit in the place where they had sat, lest I get the lepers' air [*hơ i*]; I should pour water on the floor of the restroom and on the toilet; I should not eat or drink anything in the lepers' village; and I should wash myself doubly carefully with special antiseptic soap when I got home. In addition, he instructed me to maintain some distance from the villagers at all times, because, as he reasoned, during the heat of summer, their pores would be wide open and more 'leprous' air would be emanated, on top of their heavy perspiration. One day, when picking me up from the hospital entrance, he pointed at the cafés right in front of the hospital gate, which were all owned by non-patients, and commented, 'How could anyone dare to drink coffee here? Around here it's full of lepers' creepy air . . . Disgusting! [*Thấ y ó n!*]'

Throughout my time in the field, I was to hear many people voice sentiments of this kind. The driver's comments encapsulate the most common themes. They show that, despite health education, leprosy is still seen as seriously contagious. They reveal the continued

1 Leprosy, or Hansen's disease, is a disease caused by *Mycobacterium leprae*. It affects the skin, nerves, eyes, and lining of the nose. If left untreated, the disease may lead to paralysis, blindness, deformities, and amputation. Today, leprosy is known to be only mildly contagious, and can be effectively treated with multi-drug therapy (MDT), which has been a standard cure for leprosy since the 1980s (WHO 2019). However, a large number of Quy Hòa's leprosy-afflicted residents—particularly the village elders described in this paper, who entered the Christian-run leprosarium before 1975—had the disease before MDT became available. As a result, many of them suffer from several of the severe consequences of the disease, such as disfigurements and loss of limbs.

2 Although nowadays 'Hansen's disease' is often considered the less pejorative term, 'leprosy' is used throughout this paper as it more fully reflects the illness experience of the people of Quy Hòa. In Quy Hòa, villagers normally use terms such as 'bệnh phong' [leprosy] or 'bệnh cùi' [a more stigmatising term for leprosy] to refer to their illness, and while the term 'bệnh Hansen' [Hansen's disease] exists in Vietnamese medical literature, villagers rarely, if ever, hear or use it. My choice of term is not intended to stigmatise people afflicted with the disease, but rather to facilitate analysis of the cultural and societal perception of leprosy and its role as a social symbol and metaphor.

popular acceptance of humoral and other theories about the causes of leprosy, which conflict with the biomedical explanation upon which modern medical treatment is based. They also indicate the horror and disgust that people feel towards the disease.

Mary Douglas (1969, 35) contends that ‘where there is dirt there is system’; our notions of dirt express symbolic systems that entail a set of order relations, and dirt is a contravention of that order. Dirt is therefore an anomaly that is defined, demarcated, and potentially punished, rectified, excluded, or eliminated, in order to preserve a moral and social order. Using the theoretical lens of Douglas (1969) and Victor Turner (1967) and by drawing on ethnographic research on leprosy in Vietnam, this Position Piece attempts to explain why leprosy is considered to be polluting and threatening and why stigma against people affected by this disease still persists.³ It argues that leprosy involves and engenders categorical confusion. Leprosy contagion is believed to occur during transitions, at the crossing of boundaries, or when there is a contravention to natural or seasonal order. Moreover, in advanced cases, leprosy renders its sufferers’ bodies disfigured, and thus is perceived as a transgression to the existent system of aesthetic values of bodily integrity.

First, the essay explores popular explanations for how leprosy is contracted, most of which attribute leprosy to a transgression of one kind or another. People affected by leprosy are those who have transgressed the divide normally maintained between the living and the dead, who have ventured beyond the spatial thresholds of ordinary human life, or who are victims of a transition between seasons or states. Air, water, and bodily fluids are all understood as common media of transmission.

The Position Piece then examines popular conceptions of the bodies of people affected by leprosy as ambiguous, liminal, hybrid, and ‘betwixt and between’ (Turner 1967). The fact that such bodies often cause shock and are described as ‘disgusting’ or like ‘ghosts’ [*ma*] by non-patients also clearly illuminates Douglas’s and Turner’s views on pollution and danger. The popular conception of leprosy as dangerously polluting suggests that it may be the categorical disordering engendered by the disease, rather than ignorance about its true nature, that accounts for the widespread fear and loathing that leprosy continues to arouse. This provides one explanation for why leprosy stigma continues to exist in Vietnam today, despite a highly efficient medical cure and the state’s extensive awareness programmes. The

3 See, for example, Barrett (2005); Kikuchi (1997); Leung (2009); Loh Kah Seng (2009); McMenamin (2011); Monnais (2008); Navon (1998); Ovesen and Trankell (2007); Predaswat (1992); Staples (2003); and White (2009).

piece therefore illuminates the resilience of leprosy as a cultural symbol and contributes to a more nuanced understanding of leprosy stigma in local contexts.

This essay draws upon a year of ethnographic fieldwork conducted in 2011 in Quy Hòa National Leprosy–Dermatology Hospital and the Quy Hòa leprosy village adjacent to the hospital, located in the outskirts of Quy Nhơn city in South Central Vietnam. At present, Quy Hòa leprosy village is a community of around four hundred leprosy sufferers and their families. In Quy Hòa, I collected life narratives of residents afflicted with leprosy, conducted interviews with patients’ families and hospital staff, and also participated in daily household and community activities.

Aetiology and contagion

‘*Bệ nh phong*’ is the standard term for leprosy in Vietnamese. ‘*Phong*’, a Sino-Vietnamese word, is normally understood as ‘wind’. In Vietnamese traditional medicine, ‘*phong*’ is described in the following way:

- (1) wind-evil, one of the six evils, which is the common pathogenic factors of exogenous diseases that combines with other factors to attack the human body. Its pathogenic characteristics are sudden onset, changeability, and tendency of wandering; and (2) wind-syndrome, caused by infiltration of poisonous wind and air (Trần 2000, quoted in Hinton et al. 2003, 366–367).

This explanation resonates with the widespread popular belief in Vietnam that malicious infections of various kinds are caused by the body being ‘hit’ by bad wind [*trúng gió*].

According to early accounts in southern Vietnam, wind diseases might be caused by unpredictable climatic changes. Trịnh Hoài Đức (1820), an early 19th-century observer, noted the prevalence of wind diseases in a coastal environment marked by climatic unpredictability, writing, ‘During the year, the wind and rain, cold and heat, rarely arrive at the expected times. So there are many wayward winds . . . Sicknesses often arise from the wind, and the bad air is polluted’ (quoted in Dutton, Werner, and Whitmore 2012, 273). He also recorded the effect of yin vapours arising from damp soil ‘entering the fibres of the human body and causing maladies such as leprosy’ (quoted in Taylor 2014, 10). A similar belief is shared by Khmers, as Devon Hinton et al. (2003, 363) note:

Khmer entertain fears that rainfall that arrives during hot weather will cause illness; they explain that when rain hits scorched soil, a steam rises from the ground; the steam is capable of entering the body and producing illness. Hence, Khmer

sometimes experience rain-induced panic attacks. As in the Vietnamese case, the vulnerability to weather shifts and rising steam is dependent on the perceived strength of the body.

One prevalent folk belief about the aetiology of leprosy in Vietnam holds that one might catch leprosy from newly buried tombs [*mả mới*], particularly when the soil is wet after rain. The poisonous air from below the tomb is said to evaporate, putting anyone unfortunate enough to accidentally inhale or absorb it through their pores at risk of the disease. It is often noted that the air from newly buried corpses, which are in the process of decomposing, is particularly toxic and likely to cause leprosy. There are a variety of slightly different versions of this story that embellish the core folk belief. Many of the Vietnamese people from Quy Hòa, Quy Nhơn City, and Hồ Chí Minh City who I talked to during my fieldwork added that the air from the tombs could possibly bring about leprosy if it rains after many dry sunny days (for instance, following out-of-season rain showers) because it causes the air from the soil [*hơi đất*], long dried under the sun, to evaporate and come up through the ground.

A number of Quy Hòa villagers who I met believed that they had caught leprosy from the toxic air from new tombs.⁴ Grandpa Lự a, for example, believed that he got leprosy during the years he was fighting in the army of pre-1975 South Vietnam. At times, he and his fellow soldiers had to lie down and hide behind tombs in cemeteries while waiting for communist guerrillas, sometimes for entire nights. During those chilly nights, the dewdrops seeped through the soil, which made the air from the soil and the tombs surface. Grandpa Lự a supposed that, while the whole unit was there, he was the only one unlucky enough to have lain down on a new tomb. ‘How could I possibly know which one was old, which one was new?’ he asked resentfully. The toxic air that emerged from the new tomb through the soil during the dewy nights on duty, he surmised, had caused his leprosy.

The leprosarium of Quy Hòa was established in 1929 in the Quy Hòa valley area, close to a small community called ‘upper Quy Hòa village’. The small non-patient community of upper Quy Hòa village have thus lived near leprosy patients for a long time, and have become used to it. Many of the people in the upper village have had frequent contact with leprosy-affected people in the leprosy village. In recent years, several people from the non-patient community of upper Quy Hòa have contracted leprosy. Interestingly, the elders of the upper Quy Hòa community did not explain this as a consequence of intertwined interaction between the two

4 For insightful analyses on air, wind, pores, pathogens, and poison in Vietnamese and Asian cultural contexts, see Hinton et al. (2003), Kuriyama (1994; 1999, 259), and Leung (2009, ch. 1).

communities, but rather believed it was because those people often passed by a cemetery near upper Quy Hòa village. As an elderly woman told me, many cattle-tenders from upper Quy Hòa, after taking the cattle out to the grassy mountainside, take them back via the old South Vietnamese military cemetery in the valley near Quy Hòa. According to the elders, these cattle-tenders might have contracted leprosy through the polluting air emerging from the tombs during sudden rains following the long sunny periods of the dry season.

Meanwhile, others believed that being ‘hit’ by the air from a tomb after rain would only cause leprosy if the deceased happened to be a person affected by leprosy. This belief resonates well with a widely known myth about how Hàn Mặc Tử (1912-1940), a famous Vietnamese leprosy-afflicted poet who was treated and passed away in Quy Hòa, caught leprosy when he was out on a date with his lover. It is said that the couple was happily enjoying their visit to Lầu Ông Hoàng, a well-known place in Phan Thiết, when suddenly thick, dark clouds gathered, strong wind violently blew, and it started showering heavily. The confused young couple hurriedly searched for a place to take shelter before huddling in a small corner to wait until the rain stopped. Only later did they find out they had huddled upon the newly buried tomb of a man who had died from leprosy. After that fateful date, Hàn Mặc Tử started seeing rashes and patches on his skin and was later diagnosed with leprosy.

It is also surmised within communities affected by leprosy, as well as by (judging by my own interactions) a number of people from outside those communities, that people living near coastal areas or lakes, or those involved in fishing, are more likely to get leprosy. Interestingly, none could explain why this is the case. ‘Maybe because they frequently have contact with water, or because they eat a lot of fish’, one interlocutor speculated.

In contrast to the ‘sea, lake, and fish’ theory, a remarkable number of my interlocutors both inside and outside the leprosy village mentioned ‘deep forest and toxic water’ [*rừ ng thâm nước độc*] as a hypothesised aetiology of leprosy. They explained that patients may get the disease while they ‘travel through the forest and the mountain’ [*đi rừ ng đi núi*], where there exist various sources of pollution, poison, and danger beyond the control of human beings.

Thanh, for instance, is a Cambodian-Vietnamese man who was born in Cambodia; his father was Cambodian and his mother was Vietnamese. Growing up in Phnom Penh, he had a happy and peaceful childhood until the Khmer Rouge genocide began. His father was killed and, during the turmoil, when everyone was trying to escape, he lost track of his mother and siblings. Hopeless, he did not know what to do or where to go, and so decided to flee to Vietnam, his mother’s homeland, in hope of finding her there. Thanh experienced an extremely hard trip before eventually reaching safety in Vietnam. Without any fresh water or food supplies, he ran for hundreds of kilometres, often through forests, in constant fear of

being caught by the Khmer Rouge. On several occasions he faltered and fell down due to dehydration and fatigue—but the urge to flee for survival kept him pushing forward. As he recounts:

I kept on running and running. I was too scared to stop, even though I was too hungry and thirsty. Suddenly I fell down on the slippery mud. It was painful, but looking up, I saw tens of deep footprints on the muddy forest floor. Soldiers must have run quickly through the forest and stamped strongly on the mud. Then I realised there was water contained inside the shoes' imprints, probably from dewdrops from the previous night. Without thinking for a second, I lowered my head and sipped the water.

The water inside the forest may have helped him to survive and arrive safely in the Mekong Delta in Vietnam, but, according to Thanh, now a middle-aged man, it was from those drops of water in the mud that he had contracted leprosy. As he said, the water in the deep forest may have been toxic without him knowing, but what else could he have done?

A great number of Vietnamese people, both leprosy patients and non-patients, believe that one can contract leprosy through contact with leprosy-affected people's bodies. This contact can be tactile, entail the absorption of their bodily liquids, or involve being 'struck' by the air [*trúng hơi*] exuding from their bodies. For instance, a woman in Quy Hòa explained how she contracted leprosy by wearing a leprosy-affected man's slippers. She recollected:

I walked to the market on bare foot. It was a sunny day and the ground was hot so I borrowed a pair of slippers from a man in the market to run around and play with my friends. I was a kid back then so I did not know. Only later did I find out he was suffering from leprosy.

She now guesses that she must have got infected through blood, sweat, or 'air' from that pair of slippers.

Many people I spoke with stressed that leprosy patients' bodily liquids and waste (such as urine, defecation, or perspiration) would be highly toxic, and contact with them dangerous. Sharing food and drinks from the same utensils, a common practice in Vietnam, should also be avoided because it involves exchanging saliva. The myth of Father Jean Cassaigne (1895–1973) illustrates this belief. Father Cassaigne was a Catholic missionary who established the Di Linh leprosarium in the southern Central Highlands in 1929. According to former inmates of Di Linh currently living in the Quy Hòa leprosy village, it was said that Father Cassaigne contracted leprosy from one of his dying patients while performing the last rites,

after eating sacramental bread taken from the mouth of a patient who'd died while receiving the Eucharist.

A large number of people I consulted believed that coming into contact with a leprosy-affected person when one is wounded oneself greatly increases the risk of catching leprosy. This explanation is influenced by biomedical and pathological concepts of hygiene and communicable disease. Those interlocutors presume that leprosy, like many other infectious diseases, can be contracted through blood and that open wounds may constitute gateways for leprosy to attack the human body. Many leprosy patients, as well as people unaffected by leprosy, explained to me that, if one has open injuries while engaging in tactile contact with leprosy patients who also have open wounds, the bacteria may have windows to jump from the patients' to one's own body.

As such, what theories on leprosy aetiologies in Vietnam share in common are cases of transition, transgression, and the crossing of boundaries. Moreover, advanced leprosy also renders the sufferer's body disfigured, which further causes categorical confusion.

Bodily abomination

At the beginning of my fieldwork in Quy Hòa, I raised questions about curability to a leprosy-afflicted woman while we were washing dishes together in her kitchen after a family dinner. She suddenly stopped, looked at me for a second, and responded, 'Most people here are ones who have had leprosy for a long time. Leprosy has eaten deeply into their flesh. Could fingers ever grow back?' The majority of my interlocutors in this community shared a similar opinion. For most Quy Hòa villagers, the experience of leprosy lasts for a lifetime because of the marks permanently inscribed on their bodies (see also Staples 2003). A large number of people affected by leprosy in Quy Hòa are perceived to be disabled and disfigured, and the most severely disfigured people I met were elderly leprosy-affected people who had contracted the disease decades ago when there had not been an effective cure.

Body parts affected by the disease, such as extremities or the whole or part of a limb, are often construed by both patients and non-patients as 'having been eaten' [*bị ăn*] by leprosy, and are thus said to be 'ruined' [*bị phá* or *bị hư*]. Severely wounded body parts are perceived to be rotting and thus in need of amputation. In a sense, such body parts are considered to be 'destroyed' or 'dead'. In the Vietnamese popular perception, a body which is both alive and dead is an affront to a very basic sense of what it means to be alive. Bodies of leprosy patients are therefore seen to be deeply disturbing.

What is more, the body of a leprosy patient is also a site of hybridity and ambiguity. The serious deformities typically caused by leprosy are depicted by the saying ‘leonine face, rabbit’s eyes, monkey’s hands’ [*mặt sư tử, mắt thỏ, tay khỉ*], a comparison with which residents of Quy Hòa have long been familiar. In cases where the condition results in a collapsed nose, the face of a person affected by leprosy is said to resemble a lion’s. Leprosy patients can also suffer from problems with the eye muscles; in serious cases, where patients have difficulties closing their eyes or are no longer able to completely close their eyes when asleep, they are compared with rabbits, which are often mistakenly thought to sleep with their eyes open. Moreover, in cases where leprosy leads to the loss of hand muscle in between the thumb and the index finger, affected hands are said to look like the paws of monkeys. To compare the physical appearance of people affected by leprosy to animals obviously has severely degrading connotations. To portray their condition as resembling a mix of different animal parts construes the bodies of leprosy patients as abominations—monstrous hybrids.

For some of my non-patient interlocutors, such bodily hybridity might cause confusion between life and death. Such was the case for Vy, a young lady from Quy Nhơn City who married a man from the non-patient community of Quy Hòa’s upper village. Being from Quy Nhơn, she already knew about the former leprosarium and its residents, and during their courtship period he had taken her to Quy Hòa village many times. After they got married, they moved to Quy Hòa and, on the first day, the new bride went to the market early in the morning to buy fresh food for her cooking. However, when she browsed the market—part of the community of leprosy-affected people, and the only market in the whole Quy Hòa area at that time—she flew into a panic seeing ‘people lacking fingers chopping the pork’. Horrified, she ran back home immediately, feeling sick and scared for the whole day and many days after. In retrospect, she recalled, ‘It’s a very different kind of fear that I had never experienced before. That kind of fear is like the horror of seeing *ghosts*. Seeing those people made me feel panic [*hốt ng*]. I was immediately horrified as if I had seen ghosts’.

Comparing leprosy sufferers with animals or ghosts clearly signifies reduced personhood. Moreover, the ghost-like leprosy patients can be likened to the ‘liminal *personae*’, the neophytes in the liminal period of ‘betwixt and between’ described by Turner (1967, 97) as ‘neither living nor dead from one aspect, and both living and dead from another. Their condition is one of ambiguity and paradox, a confusion of all the customary categories’. With bodily symptoms that disturbingly signify suspension between life and death, a person with advanced leprosy is suspended in categorical liminality. As Turner (1967, 97) argues:

Transitional beings are particularly polluting, since they are neither one thing nor another; or may be both; or neither here nor there; or may even be nowhere (in terms of any recognised cultural topography), and are at the very least ‘betwixt and between’ all the recognised fixed points in the space-time of cultural classification.

Both bodies affected by leprosy and Vietnamese folk beliefs of leprosy aetiologies focusing on new tombs and newly buried corpses reverberate with this theory of pollution. Dead bodies in the process of decomposing are such ‘transitional beings’ (Turner 1967), in the liminal period of hybrid, ambiguous status. Newly buried corpses are not human anymore, but they have not yet vanished. They are not alive, but they are not yet gone. Dead bodies newly buried under new tombs are thus conceived to be particularly polluting and toxic. Meanwhile, bodies affected by leprosy are still alive but with parts considered ‘eaten’, ‘ruined’, or ‘rotting’. Violations of the moral ordering of time and space—such as those brought about by untimely weather; warfare; transgression into the margins; or breaches of moral, physical, or social boundaries—perilously expose one to leprosy contamination. Persistent attitudes conflating the aetiologies and consequences of leprosy in Vietnam with sufferers’ transgressions to order ineluctably render those named with this condition as impure.

Conclusion

Drawing from Douglas’s (1969) and Turner’s (1967) work, this essay has shown that leprosy is perceived as a major source of pollution and danger because it is a contravention of the order system that has long sustained Vietnamese society and culture. In the terms proposed by Douglas, the sufferers of leprosy appear to be ‘out of place’, ambiguous, mixed, or hybrid, and hence are considered polluted. Understanding leprosy in Vietnam through Douglas’s and Turner’s theories also clarifies one of the reasons why it is difficult to eradicate persistent leprosy stigma, despite a highly effective medical cure and extensive state efforts to erase stigma and socially reintegrate residents of leprosy sufferers’ communities. As this Position Piece has shown, leprosy is symbolically polluting. Leprosy, more than a medically defined disease, constitutes a cultural category for pollution.

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