One afternoon, I was sitting with Grandpa Thiện in front of his house. He looked happy that afternoon, blissfully watching a whole new batch of chickens born a few weeks before. The quiet yard in front of his house was animated by cheerful, chirpy little chickens running around here and there. Grandpa Thiện was proud that his stock of chickens had increased remarkably with each batch of newborn chicks, and he was hopeful that the price of chickens remained stable, so that when they grew up, his wife would be able to sell them at a good price.

He told me about his niece, who was blind. She studied well and was able to become a teacher. She used to have a boyfriend who was not blind, but the relationship did not go anywhere because his family could not accept a blind daughter-in-law. The boyfriend broke up with her several years later to marry someone else. Then she met a blind man. Even though they could not see each other, they understood each other well. His family adored her too. They finally got married and lived very happily together.

1 Pseudonyms are used throughout this chapter.
Drawing upon his niece’s story, Grandpa Thiện stated, ‘You see, chickens stay with chickens, ducks stay with ducks. It should be that way.’ He continued, ‘Like here, people with leprosy should stay with people with leprosy. It’s very difficult for chickens to stay with ducks.’

Grandpa Thiện is one of around 1,000 residents of Quy Hòa Leprosy Village in South Central Vietnam. Quy Hòa was established as a leper colony in 1929 by French Catholic missionaries. Located in a valley by the sea in the outskirts of Quy Nhơn, Bình Định Province, the leprosarium provided a sanctuary for people afflicted by the disease and a clinic for the administration of treatments. Until the introduction of sulphide-based drugs in the 1960s and more effective multidrug therapy in the early 1980s, treatment options for leprosy were limited (Monnais 2008). The disease progressed through the appearance of numb patches and skin rashes, lesions and ulceration, and disfiguration of the face and hands. Owing to the absence of sensation in their limbs, sufferers who engaged in everyday activities such as cooking, farming or sport were prone to injury and amputation was frequently required to deal with severe injuries and chronic infection. Perhaps even more significant side effects of the disease were the fear and stigma provoked by its symptoms. Many leprosy sufferers who came to leprosaria such as Quy Hòa for treatment settled there permanently, seeking a refuge from the shame and social ostracism that accompanied the disease. After national unification in 1975, the leprosarium was taken over by the state, becoming the Quy Hòa National Leprosy-Dermatology Hospital. As of 2013, the leprosy village, located adjacent to the hospital, is home to 426 leprosy-affected people and their families, who subsist on small-scale livelihood activities, a modest patient subsidy, and charity gifts.

Since the introduction of multidrug therapy in 1983, leprosy patients in Vietnam have been able to be medically cured after only six months to a year of treatment. Moreover, in tandem with improvements in early diagnosis, advanced cases of leprosy in Vietnam have consistently decreased since 1995 (Hồ Hạnh 2010).² Provided that they have been treated in a timely manner, people contracting leprosy have been able to avoid bodily residues and thus the social stigma

² The new case detection rate decreased from 3.44 new cases in every 100,000 people in 1995, to 0.48 new cases in every 100,000 people in 2006. The leprosy prevalence rate also went down from 6.71 to 0.04 cases in every 10,000 people between 1995 and 2006 (Hồ Hạnh 2010).
attached to leprosy. New leprosy patients in Vietnam are now treated and monitored in their residential communities and are no longer isolated for treatment in segregated leprosy villages (làng phong), such as Quy Hòa. Nevertheless, there are still around 18,000 people living in leprosy villages across the country, who, although deemed to have been cured, are seriously disabled and unable to return to their original communities (Hoài Hương 2010). Most of the elderly people living in Quy Hòa had contracted leprosy before multidrug therapy was widely used in Vietnam. Although they have long been free of leprosy infection, most of them are afflicted with visible deformities and disabilities caused by advanced leprosy, and consistently expressed their wish to remain in the village.

‘Here, everyone is like everyone else!’ (‘Ở đây ai cũng như ai!’) is the response I repeatedly received from villagers after asking them why they wished to stay in an exclusive leprosy village such as Quy Hòa. Members of the Indian leprosy-afflicted community of Bethany studied by James Staples (2007) referred to themselves as people of ‘one disease, one caste, one religion’. Similarly, people of Quy Hòa leprosy village describe themselves as ‘of the same kind’ (‘cùng môt thục’) and define their community by ‘sameness’. Wherever I went in the village, people stressed their sameness — the same disease, the same life history, the same body, the same pain, and the same suffering. I came to understand ‘sameness’ as, first and foremost, the intrinsic factor that ties them all together.

This chapter tells leprosy-affected people’s stories about sameness. It seeks to elucidate the conceptions of sameness held by residents of this exclusive village of leprosy sufferers, and how sameness as a defining characteristic of the community has reconfigured their lived reality of leprosy. It draws upon a year of ethnographic fieldwork conducted in Quy Hòa in 2011, during which I was welcomed into the homes and lives of numerous leprosy-affected villagers and their families. Over the course of my research, I collected life narratives of Quy Hòa residents afflicted with leprosy, while also observing and taking part in community events, meetings, rituals and daily activities. My research also took me to other communities of leprosy-affected
people in southern Vietnam, and to the urban and peri-urban sites where people with enduring physical residues of the disease live and work.3

Drawing upon the villagers’ conceptions of their own community, this chapter seeks answers to the question of why exclusive communities for people with leprosy still exist now that leprosy has been declared medically curable, and as only mildly contagious, and when ‘community-based’ and outpatient treatment has replaced segregated institutional care as the preferred public health approach to treatment. The chapter shows that while the medical rationale for segregation no longer exists, the existential problems leprosy sufferers continue to endure provide justification for their continuing attachment to such communities.

The chapter argues that community is a therapeutic antidote to the slights and injuries visited upon those with leprosy in the wider society. For people shunned and feared as threatening to the normal social order, such a community exists as a space of protection. For people displaced from their families and villages by their social invalidity and the emotions aroused by their physical disfigurement, the village provided an opportunity for social re-integration. For those gazed upon obsessively for their bodily difference, exclusive living continues to offer the powerfully redemptive experience of sameness. Such collective solutions have been arrived at through turbulent personal processes of banishment, degradation, withdrawal, re-emplacement, hope and reinvention.

The chapter illustrates these points by describing elderly Quy Hòa residents’ experiences of intimate exile and the denial of relatedness with members of their own family. It describes the expulsion of leprosy-affected people from their communities and the social death meted out to so many with this disease — traumatic experiences that still haunt and unite those who endured them, irrespective of their social background. The chapter discusses how the value of ‘sameness’ arises out of newly discovered feelings of mutual sympathy

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3 The fieldwork was conducted as part of my PhD in anthropology at The Australian National University. I wish to thank Philip Taylor for his guidance on my project and for his extensive comments on the argument of this chapter. I also am grateful to Assa Doron and Kirin Narayan for providing advice and encouragement in my writing, and to the anonymous readers who reviewed an earlier version of this chapter.
and love for those who are similarly social outcastes. The cases also demonstrate the empowerment and confidence that come from living in a community made up of people exclusively like oneself. I argue that the power of sameness, of being with identical others, and of living in a community where all people are alike, has a reassuring and healing effect that helps account for residents’ attachment to life in this exclusive leprosy village.

**Intimate Exiles**

People in Quy Hòa come from all walks of life. While a large number of villagers are from poor rural areas, a few inmates of the leprosy village came from wealthy and illustrious families. One of them is an old man, Grandpa Tâm, the nephew of L., who stood out as the only Vietnamese general in the French colonial military among the many French generals and officials in the colony at that time. Needless to say, back then, this General’s family was very well-known, highly respected, and powerful. Very few people, however, knew about his nephew, a leprosy sufferer sent into Quy Hòa.

One day, the inmates in the then Catholic-run Quy Hòa leper colony heard the news that the General, Grandpa Tâm’s uncle, would be accompanying King Bảo Đại to visit Ghềnh Ráng, a beautiful beach area not far from Quy Hòa. Grandpa Tâm was coaxed by his fellow inmates into going there to meet his uncle. He escaped from the leper colony through the fence on the cemetery side, walking along the narrow trail around the hill that separates Quy Hòa and Ghềnh Ráng beach, and finally reached Ghềnh Ráng, where the King and the General were visiting. Grandpa Tâm bravely asked the entourage to let him come over and see the General, identifying himself as the General’s nephew. However, the General rejected him, curtly denying having a nephew suffering from leprosy. As soon as this disavowal was uttered, members of the party severely chided the ‘leper’ and rudely told him to take himself someplace else.

After the trip with the King to Ghềnh Ráng, the General’s rage continued to fester, and he vehemently reprimanded his sister, Grandpa Tâm’s mother. He asked his sister to tell her leprosy-affected son to stay put in Quy Hòa, and never again come out and tell people that he was the General’s nephew. He was such a powerful man in the French colony
at the time; if people knew that he had a ‘leper’ nephew, it would be a big ‘loss of face’ (mắt thể diện) and bring serious shame for not only him but the entire family.

The fury of the General and his family was conveyed to the leprosy-affected nephew, Grandpa Tâm, in a letter sent into the leper colony, which told him to henceforth stay within Quy Hòa. If he needed money, his mother would send more money for him, but he could not go out. Back in Quy Hòa, after the venture out of the leper colony and the humiliation of being disowned and sent away by his powerful uncle, Grandpa Tâm was very sad and felt pity for himself (tều thân). Seeing him coldly rejected and expelled, his fellow inmates in Quy Hòa realised that even though they were born into very different backgrounds — he was from an extremely influential and prestigious family while most of them were poor peasants — once they became ‘lepers’, they all became the same. The spirit of egalitarianism encapsulated in the villagers’ own words, ‘Here everyone is like everyone else’, has acted as salient rhetoric in this community’s life since its inception. Regardless of how different they had been as individuals, as lepers they were bound to the same destiny. As Louisa Howe (1964) suggests, a community can be forged by symbolic understanding of a common destiny. In Quy Hòa, this strong sense of a shared fate, reflected through such stories as the one above, and also as regularly mentioned in villagers’ self-description as people with the ‘same lot’ (đồng cảnh ngộ) or ‘same fate’ (cùng chung số phận), contributes to robustly sustaining the community.

Many people in Quy Hòa leprosy village shared with me their belief that most of the time they could only feel completely comfortable and open around people with the same disease. Many are very reluctant to enter social relationships with non-leprosy patients outside their exclusive network of leprosy sufferers. The family of my village friend, Hà, whose parents both had leprosy, is no exception. She proudly told me that she was very popular with boys when she was young. She had many followers, but she liked one man from a non-patient family in the upper village of Quy Hòa.

Hà was very happy when the man asked her to marry him. However, her leprosy-afflicted mother strongly rejected the idea and insistently advised her to choose the son of a leprosy-affected person, like her. Her mother believed that if Hà married into a non-patient family,
her spouse’s family would look down upon them. Her mother poignantly asked her, ‘They can hold a glass of water in one hand, while I have to use both hands and yet barely manage to hold a glass. Just think, how could I ever talk on an equal level [nói chuyện ngang hàng] with them?’

Eventually, listening to her mother’s advice, Hà did not marry the man from the upper village, but married the son of a leprosy-affected couple in Quy Hòa leprosy village. A few years later, the brother of the man from the non-patient family who used to be a love interest of Hà also married a daughter of leprosy sufferers in the leprosy village. His mother tried hard to prevent him from marrying someone from the leprosy village, but this was in vain, as the pair were very much in love and were strongly determined to get married, regardless of the parents’ rejection of the idea. The man told his mother that he would die if he could not marry his intended. Finally, the upper village mother had to comply with the young couple’s wish and reluctantly approved their marriage.

Soon after their wedding, the wife (the daughter of the leprosy-affected family) fell pregnant and gave birth to a boy. After giving birth to the first child, according to local custom, the daughter-in-law returned to her parents’ house and the new mother and her infant were taken care of by her leprosy-affected mother during the first few months. The husband’s mother was also excited about her new paternal grandson, the highly valued eldest son of the eldest son (cháu nội đích tôn). Nonetheless, what was frowned upon by people in the leprosy village was that whenever she came down to Quy Hòa to visit her new grandson, she always brought a clean bath towel from her house. Whenever the baby was handed to her, she put the infant onto the towel, and never let the baby’s back make direct contact with her own arms.

People from the leprosy sufferers’ community pointed out that this woman felt such aversion towards her own grandson because most of the time he was held by his leprosy-affected maternal grandmother and her daughter. That was why she never let the baby make direct contact with her own skin. Talking scornfully about that old lady from upper Quy Hòa, Hà’s mother patted her daughter on the shoulder: ‘You see, I was right to prohibit you from marrying that lady’s son. She was disgusted even by her very own grandson, let alone us!’
After getting to know me well, my village friends revealed that their ultimate wish was to be seen as equal, or ‘on an equal level’ (*ngang hàng*) to other normal people. The utmost pain of having leprosy, as lived and told by villagers, is to be seen as lesser and to be denied full personhood. Grandpa Bảo told me with an angry tone, ‘Once one gets this disease, one can never be the same as other people any more. People cannot treat you the same way as they treat normal ones.’ To illustrate, he told me about Uncle Hậu, the head of the upper village, who is married to the daughter of a leprosy-afflicted couple in Quy Hòa leprosy village. Having lived in the upper village all his life and being married to a leprosy sufferer’s daughter, he has long been used to leprosy-afflicted people. He is usually ‘natural’ around leprosy-affected people, Grandpa Bảo commented. Whenever Grandpa Bảo visited his house, Hậu was friendly and welcoming. However, once while Grandpa Bảo was visiting, another friend of Hậu’s, a non-patient, dropped in to visit and his host’s face suddenly changed. He looked confused and somehow embarrassed. Noticing Hậu’s attitude, Grandpa Bảo quickly stood up from his chair, told Hậu that he would come again another time, and left. Grandpa Bảo resentfully realised that even though Hậu behaved very ‘normally’ to people with leprosy, he could not treat his leprosy-affected friend equally to his non-patient friends.

Grandpa Thiện once confessed to me that he only needs a (non-patient) person to look straight into his eyes and say ‘hello’ for him to be really happy. What people suffering from leprosy need, he implied, is normal treatment and respect without that stigmatising stare or shunning. My village friends’ stories essentially demonstrate their profound wish to be the same, to be normal and to be equal, to stand ‘on an equal level’ (*ngang hàng*) as everyone else. Hà’s mother, as described above, could not approve of Hà’s marriage into a non-patient family, no matter how hard Hà tried to persuade her, because she could not accept a presumably unequal relationship with her daughter’s prospective in-laws. The basis of this unequal relationship, she assumed, would be the inevitable focus on her defective and malfunctioning body in stark contrast to the intact bodies of the other family. Only when Hà married another village boy, who was also the son of leprosy sufferers in Quy Hòa, did Hà’s mother feel equal to her counterpart. Her daughter’s marriage would be more sustainable, she believed, if the two families were equal.
Some village friends emphasised to me that they only feel comfortable and equal within their exclusive community and interacting among fellow leprosy sufferers. ‘Here everyone is the same’ means that no one is seen as lower than anyone else. In such a ‘normalising’ social world (Kelleher 1988), leprosy-affected people’s intrinsic desire to be seen equally as full, complete people can be fulfilled, spoiled personhood can be replenished and recovered, and dignity returned. Explaining the reason for villagers’ willingness to convert and commit to Christianity, a senior nun of the Quy Hòa Franciscan convent said to me, ‘These are the people who have suffered so much from society’s maltreatment. First and foremost, Christianity sees them fully as a person, treats them with dignity [nhân phẩm] and cares for them while everyone else is scared of them and no one cares for them.’

Social Levelling

Quy Hòa villagers’ description of their community — ‘Here everyone is like everyone else!’ — encapsulates a widely shared sense of sameness. This sentiment has been forged not only in the context of villagers’ common physical suffering and their long-term relations with each other within the exclusive leprosy village, but even more poignantly in reference to the experiences of mistreatment that each had endured before entering the village. Listening to the life stories of Quy Hòa residents, one can trace that sentiment of sameness as borne out of a shared experience of social exclusion. I turn to the life stories of Grandpa Bão and Grandpa Chân to illustrate this point.

Grandpa Bão and Grandpa Chân both came from the same village in rural Quảng Nam, a province in Central Vietnam. Nevertheless, in colonial Vietnam, their lives were starkly different. While Grandpa Chân was the son of a wealthy and powerful landowner (địa chủ) family in their region, Grandpa Bão was an impoverished landless peasant. Chân’s family owned a very large area of land, which they leased out to landless peasants such as Bão’s family. Peasants worked on their rice fields, and were required to pay back a hefty amount of harvest to the landowner family as ‘rent’ for use of their land. Normally this rent was so unreasonably high that eventually the peasants were left with only a small portion of the rice that they had toiled hard to
produce, while the landowner family increasingly became richer over time. Chân’s elder brother was the deputy police chief of the province, an influential man who added to the family’s power.

Meanwhile, Grandpa Bảo was far less fortunate. He lost both of his parents during his early teenage years and subsequently lost four of his five siblings. Eventually, there were only two members left out of his family of eight: himself, and the sister born right after him, Grandma Nga. As an orphan from a very young age, he had to struggle hard to survive and to support his younger sister. Despite always working very hard, Grandpa Bảo was an impoverished peasant.

The lives of Chân and Bảo were in such stark contrast, but they shared one thing in common — they both had leprosy, and their disease became known to villagers at around the same time. The experience of leprosy of an impoverished peasant and a son of a wealthy and illustrious landowner family significantly diverged. While Grandpa Bảo essentially experienced a ‘social death’ and painful humiliation as soon as his disease was exposed, Grandpa Chân was much better insulated by his family’s wealth and power.

In rural Central Vietnam where Grandpa Bảo and Chân are from, agricultural work used to be based on mutual help and reciprocation. People in one community helped each other in labour-intensive farming tasks such as weeding, ploughing, and harvesting. If someone received help, they would be obliged to return that person’s labour. Such contributions were calculated in labour days (ngày công) and one had to return exactly how much one had received. The reciprocal system (đôi công or văn công) worked well for most villagers; everyone could complete intensive farming work that individuals or families, working alone, could not have undertaken. However, those who could not contribute labour, such as the elderly, the sick, or the handicapped, were left out.

Leprosy sufferers were among those left out of the active labour-exchange circle. Debilitated by leprosy, Grandpa Bảo could not work in the rice fields anymore. He recalled the process of being excluded from the productive community:

Before, a lot of people came to work for me. What fun it was! When I needed help, men, women and children, so many came. But when I fell ill and could no longer work for others, no one came to help me...
anymore. At first, a few still came, but gradually there were less and less people. Finally my rice field became completely empty; there was no one. I could not work for anyone, so of course no one came to work for me.

Not only because of leprosy stigma but also due to his inability to reciprocate the agricultural work of others, Grandpa Bào gradually became economically defunct and a social outcast in his community.

Faced with hunger, he had to wander around the village, wading in the flooded rice fields to catch fish, strolling along the village roads to pick star fruit or bananas, and looking for anything edible to satisfy his pressing hunger. His hands were already clawed and weak; in order to climb trees to pick fruit he had to press his chest hard against the tree bark for added grip. He did not feel that much pain owing to his numb skin, but his chest ended up being scratched, bruised and bleeding, which made him appear even scarier to other villagers.

A twist of fate saw his only surviving sibling, his sister Nga, also suffer from leprosy. One day while she was in the nearby market town of Hội An buying some herbal medicine believed to be helpful for leprosy, the villagers got together and destroyed her house so that she could no longer live in their neighbourhood. Having nowhere else to stay, she was forced to live in a tiny hut at the edge of the forest, far away from the village. Meanwhile, since Grandpa Bào was now alone, he had to fetch water from the village well on his own, even as his skin injuries worsened. Each afternoon, he had to bathe in the river that flowed by their village. Grandpa Bào had to expose himself on a daily basis to the villagers’ eyes in order to undertake necessary activities such as foraging for food, bathing, and fetching water. Moreover, he had no other choice but to continue using the communal resources: fetching water from the village public well, bathing in the river, catching fish from the paddy fields in the village, and picking fruit from the trees that lined the village roads. His daily appearance in public spaces and his heavy reliance on communal utilities and natural resources, magnified by his debilitating illness, acted to intensify villagers’ concern and anger at the ‘leper’.

Meanwhile, as his family was very rich, Grandpa Chân never needed to work, to exchange labour with community members, or find food or fetch water by himself. He lived in a spacious two-storey house surrounded by a large garden. Since Chân developed leprosy symptoms,
he stayed at home inside his family’s big and well-insulated house. His own room on the second floor was far away from the villagers’ eyes. Food was prepared and brought to him by the family’s servants. If he needed something from the outside, he could ask one of the family’s servants to fetch it for him. As the wealthiest family in the community, Chân’s family had their own private well and bathing facilities, so he did not have to share the public well with others or bathe in the river. Even though the villagers were afraid of and gossiped about Chân’s leprosy, he was not perceived by the community to be as intimidating as Grandpa Bảo.

Grandpa Chân’s social experience of leprosy was also less confronting and torturing because of his family’s power and influence in the region. While the villagers’ banishment and exclusion was overt and was strongly directed against Grandpa Bảo and his sister, Grandma Nga, villagers whose livelihood heavily depended upon Grandpa Chân’s family, the powerful landowner, never dared to explicitly exhort the banishment of Grandpa Chân. As Grandpa Bảo recalled, the villagers trying to expel him from the community called him ‘that wretched leper’ (thằng cùi) and directed their anger to him, saying, ‘Send that wretch Bảo away! He stays here and pollutes our village. If we let him stay here, he will spread leprosy to us and our children!’ Villagers added pressure on his relatives to send him away. However, Grandpa Bảo recollected that in a village meeting to discuss sending Grandpa Chân away, the most villagers could do was to generalise about leprosy patients in the area: ‘The lepers living here are a source of illness and a threat to all of us. They are polluting our village. We should try to get them to go away.’ Everyone attending that community meeting understood that the ‘lepers’ mentioned included Grandpa Chân, but no one dared to overtly name him as one of the polluting ‘lepers’ they wished to expel.

When Grandpa Bảo eventually left the village for Quy Hòa, he left in profound pain, shame, and anxiety. After one year, when he was allowed to come back for a short visit, he was shocked to see that his house had disappeared. As soon as he had gone, he was told, the village men — mainly his cousins and relatives — had immediately destroyed his house. All that was left of his previous house was the roof, lying on the small plot of land where his house used to be. When he asked about this, his cousins reluctantly explained that they had dismantled the house in order to preserve the wood, lest it be eaten by
termites over time. However, he knew for sure that this was an excuse, because although they had dismantled the house they had left the roof out in the open where it continued to be eaten by termites. Ultimately, he understood that the destruction of the house was a collaborative expulsion plot by the villagers to ensure that he did not return to live in the village.

Meanwhile, as a high-ranked police officer, Grandpa Chân's elder brother was well-travelled and had a wide professional network. That was how he knew about the Christian-run leper colony of Quy Hòa. He decided to send his younger brother there. Grandpa Bảo still remembered the day when Chân left for the leper colony, around one year before he also left for the colony. He was among those who observed the departure of Chân and his entourage from afar. When Chân left, many family servants and villagers who worked on his family's land had to accompany him and send him off to the car. The family servants had to carry his suitcases to the police car that was sent to pick him up by his elder brother, while another was holding his hat. When he got into the car, everyone respectfully said farewell to him and wished him well.

Yet the respectful attitude of the servants and villagers did not mean that they were not scared or did not feel disgusted, Grandpa Bảo added. He knew that the villagers who were servants at Grandpa Chân's house, and who had to serve him, always washed themselves carefully after coming home. Sometimes the landowner family gave them some leftover rice from the family meals, wrapped in banana leaves. Although they felt nauseated, they never dared to reject the gift and always politely received the food. However, they would never eat the food from the leper's family and would feed it to their dogs at home, even though they were very poor and rice was seen as precious.

It was not true that Grandpa Chân did not feel sad and pained because of leprosy. Even though his family was wealthy and he had servants to help him, most of the time he was confined to the second floor of his house in order to avoid the eyes of villagers. Yet the most profound hurt for him was being abandoned by his fearful wife, who ran away after he contracted leprosy. No one knew where she escaped to, but many speculated that she had travelled very far away to the south,
so that no one could find her. After Chân’s wife left him, he was deeply saddened and felt very lonely, which eventually led to his decision to leave the family and enter the leper colony.

Being from the same community, Grandpa Bảo and Grandpa Chân had known each other since they were children. Yet at home in Quảng Nam, they had rarely talked to each other. At that time, Bảo was only a young orphan and a poor peasant, while Chân was the son of the most powerful and wealthy family in the region. When they happened to meet, knowing his superior position, Chân talked very little to Bảo, or domineeringly asked Bảo to do this and that for him. Being born and raised in an illustrious landowner family, Chân embodied superiority and arrogance over the other peasant villagers.

It was only since they came to Quy Hòa leper colony that they really became brothers (anh em), Grandpa Bảo recollected. Entering Quy Hòa, Grandpa Bảo was first horrified by the horrendous bodies surrounding him, but after some time, he realised that here everybody was the same. Grandpa Chân’s previous life as a treasured son of an upper-class wealthy landowning family, and Grandpa Bảo’s previous life as an orphan and an impoverished peasant, faded away. The socioeconomic gulf that divided them in their life outside suddenly did not matter anymore.

It was at the leper colony that Grandpa Chân started talking to Grandpa Bảo as an equal friend. He liked to talk and share things with Grandpa Bảo, probably because they had been neighbours back home and shared a lot in common. Now, two of them could sit together at the same table to drink some tea or share meals together, something that would have been impossible if they were still living back home, Grandpa Bảo commented. At first, Grandpa Bảo was even surprised when Chân invited him to his house for a death anniversary of one of Chân’s ancestors (đám giỗ). But there, sitting on the same table and sharing the same meal, Chân openly affirmed to Bảo, ‘Now, carrying this disease, I am like you, you are like me’ (‘tôi cùng nhút anh, anh cùng nhút tôi’). He stated their sameness and equality. As such, there was no one superior or inferior, since what connected them was the disease that they shared, and the same exclusive community in which they both took shelter. Here at Quy Hòa, the previous social hierarchy and
Social Detachment

The stories of Bào, Nga, and Chân demonstrate how the village of Quy Hòa acted as a safe haven for people afflicted by leprosy and who, in addition to enduring the debilitating physical aspects of the disease, had also suffered the blows of social devaluation and expulsion. However, not all people were so cruelly cast out from their former lives and networks. A significant number of villagers I met had elected to leave their former lives of low self-worth and self-stigmatisation. Out of a sense of shame, they disengaged from social relationships and sought sanctuary in Quy Hòa as a community of self-exile. The social status of Quy Hòa villagers became erased and replaced by a homogeneous identity defined by their illness. Villagers’ common description of their community — “Here everybody is the same!” — not only speaks to their sameness but also underpins another important factor: their presumed equality and homogeneous identity.
his leg was amputated because of leprosy and replaced with a prosthetic limb. Besides that, however, he does not have other typical deformities caused by the disease, such as clawed hands.

Yet he always feels profoundly different as a leprosy-affected person. Those who knew his wife described her to me as a ‘virtuous woman’ who stayed loyal to him and took good care of him after he contracted leprosy. But several years after he was first diagnosed with leprosy, he was determined to leave her. She was broken-hearted and insistently tried to convince him to let her stay, but he adamantly rejected her. He left behind his wife and children, and went alone into a leprosy village in Sóc Trăng. Years later, he met Father Thọ, the founder of the ‘Tam Hiệp leprosy neighbourhood’ (Xóm cùi Tam Hiệp), as this area crowded with leprosy sufferers in Biên Hòa is known to city dwellers. Grandpa Tùng followed Father Thọ into Tam Hiệp, settled down and devotedly assisted the Father in simple day-to-day leprosy care for the residents, such as tending skin wounds, changing bandages, or sanitising ulcers and wounds. He has worked dedicatedly for the Father and for his community for decades. Father Thọ and this neighbourhood are his new family, he explained. Over the years, never again did he contact or go back to his wife and children.

Now that Father Thọ has become old and weak and is regarded as a symbolic fatherly figure to the community, rather than the proactive patron directly involved in daily care for the community that he used to be, Grandpa Tùng is planning to retire. Some of his elderly friends in the community tried to convince him to go back to join his family, who still wait for him and obtain news about him through his friends, but Grandpa Tùng refused. Instead, he wanted to enter a completely exclusive community for leprosy sufferers such as Bến Sân, not far from their Tam Hiệp neighbourhood in Biên Hòa. Another elder commented to me that they felt pity for Tùng and his wife:

He felt too serious about his leprosy, but he should not feel that heavy (nảng nè). He can easily go out and tell people he is a war invalid. His limbs are all very clean and look okay. He looks just like a war invalid with his prosthetic limb; no way are people able to know that he had leprosy. But he was determined to leave his wife, and now he even wants to move into Bến Sân. His family love him but he always rejects them. Poor things!
Grandpa Hai, a respected elder in the Tam Hiệp community, also told me about his plan to move into an exclusive leprosy village such as Bến Sán to spend the last years of his life and avoid ‘causing trouble’ (làm phiền) for his children. He always felt bad about his son and daughter, regretting that having leprosy-affected parents had brought great shame and trouble for them. His son had dated his wife for eight years, from high school until marriage, but not once did he take her back home to introduce to his parents. When their son decided to get married, Grandpa Hai and his wife were extremely anxious. Their son’s girlfriend and her family did not know about Grandpa Hai and his wife. Grandpa Hai and his wife worried whether the girl and her parents would still want this marriage if they knew that the pair had leprosy. Grandpa Hai felt too ashamed of his leprosy-ruined body to appear at the wedding as the groom’s father. His wife had milder leprosy than him, and when she covers the scars with long-sleeve tops and pants, few people could actually recognise that she had leprosy.

Grandpa Hai has a higher level of deformities: his hands are clawed and lack several fingers, and one of his legs has been amputated and replaced with a prosthetic limb.

Grandpa Hai was extremely worried and could not sleep for weeks. Then he came up with an idea: they would lie to the bride’s family and say that the father had already passed away. The whole family sat down together to discuss his plan, but his wife rejected it, saying it was ominous to say that he was dead. Finally, they decided to tell the other family that the father had run away with his mistress, leaving behind his wife and children, and that they had never heard from him since.

For their son’s wedding, they asked a male relative to pair up with Grandpa Hai’s wife to represent the groom’s family. Half sulkily, half regretfully, Grandpa Hai told me about the weddings of his son and then of his daughter: ‘Every time our children got married, my wife had to hurriedly pair up with a man!’ On his son’s wedding day, Grandpa Hai recalled, he nervously hid himself at home all day long, feeling pity for himself. Yet at the same time he felt happy, because his son could finally get married, something he had never even dared to dream of during his younger years when he had struggled with this illness. At that time, Grandpa Hai did not think he could ever get married, let alone have children. When their children were first born, he and his wife were worried about their marriage prospects. But in
the end, Grandpa Hai was very happy that both of his children were happily married, and now he has little grandchildren who he adores very much.

Yet Grandpa Hai’s family could not hide their secret forever. One day, a couple of years after his son got married, Grandpa Hai was genuinely astonished when his daughter-in-law’s parents suddenly appeared in front of his door. They came to find him, to ‘offer greetings’, and to tell him they were happy to see him. ‘They talked to me respectfully’, he recalled, ‘and told me I should not have hidden myself. They said we are xui gia [the parents of one’s son’s or daughter’s spouse]; we are all connected.’ Grandpa Hai told me he was so embarrassed that he did not know how to respond or what to do.

Grandpa Hai and his wife still live in Tam Hiệp neighbourhood because, as he said, his wife helps to take care of the grandchildren, who are all still very young. Thinking about the future, similar to Grandpa Tùng, Grandpa Hai and his wife plan to leave this neighbourhood for a completely exclusive life with other leprosy-affected people in Bến Sán leprosy village. He is afraid that one day, no matter how much he tried to hide himself, his children’s colleagues and friends could eventually find out about him, just like his son’s parents-in-law had done. This would ‘cause trouble’ (làm phiền) for his children and disturb their careers, he believed. At the time we talked, his son had been promoted to the position of deputy head of his department in a state institution, and had just become a Party member, which would pave the way for his further promotion. Grandpa Hai was worried that his son’s promising career prospects might be hampered if his colleagues knew about his leprosy-afflicted parents. Even though Grandpa Hai is living in a neighbourhood crowded with leprosy-affected people like him, he still feels somehow nervous of being discovered by his children’s colleagues and acquaintances: ‘You see, anyone can ride their motorbike into this neighbourhood. I want to enter a leprosy village and live there until I die, so no one can find me. I want them to regard me as an already dead person.’

In his research in Northern India, Ronald Barrett (2005:222) observes that sadness and resignation were pervasive emotions among the residents of the leprosy treatment centre where he did fieldwork. Predaswat (1992:54) cites a study on leprosy in Thailand (Leerapun 1989) in which the authors found that self-stigma precedes
negative societal reaction. In her own research conducted in Noan Pa village, Thailand, Predaswat also observed self-stigmatisation among her leprosy-affected informants (Predaswat 1992:138). She found that sufferers’ low self-esteem and social withdrawal stems from the cultural construction of leprosy in Thailand as impure and sinful. Because they know that leprosy results in social ostracism, they believe they are social outcasts (Predaswat 1992:138), which resonates well with Nancy Waxler’s (1981) thesis that patients’ response and adaptation to leprosy are primarily culturally conditioned.

Self-stigma is similarly prevalent among the leprosy-affected people in Vietnam who I met. Being sad and conscious about their difference, many have rejected relationships with families and friends, and have withdrawn into communities of people like themselves, in whose company they could find comfort. This withdrawal has its negative effects for it has hampered their social relationships and their prospects for reintegration. Nevertheless, the process of disengagement has not brought about their social death, for many have rebuilt relations and have found a new sense of empowerment and self-worth in their new community. This chapter will now examine these processes of personal reconstruction.

**Love Among One’s Own Kind**

Grandpa Bảo told me about the day he arrived in Quy Hòa and was taken to his assigned house in the leper colony. On the village road he saw small groups of inmates sitting and chatting together. When they saw him arriving with two other patients, they blithely pointed at them, calling out, ‘More of the same kind!’ (‘Rồi, cùng mốt thú rồi!’).

In the days after his arrival, he got to know more about the leper colony inmates who now became his neighbours. It was easy to mingle and befriend people here, the old man recalled. Seeing him strolling by himself on the village road, his fellow residents waved their hands and called to him to stop by. They asked him which province he came from, and how he found his way to the leper colony.

He quickly made a lot of friends in the leper colony. It had been very long, Grandpa Bảo recalled, since he had a friend or was approached by friendly people who wanted to talk to him and get to know him.
His bitter memories as a lone ‘leper’ back home in Quảng Nam Province were still clearly imprinted in his mind — as soon as people saw him at the other end of the village road, they turned their backs and started walking quickly in the opposite direction. As soon as he appeared at one end of the paddy field, the farmers dispersed, moving away from him. Grandpa Bảo remembered the profound feelings of hopelessness and of being completely alone, without any caretakers or friends, when his limbs were already curled and weak. Sitting in his house all day long, he sadly kept looking at the sun’s rays moving from one corner of his little house to the other, from morning to afternoon, everyday. All he could think of at the time was — his tone lowered when he told me about those dark days — how to kill himself. He went out to the river, planning to jump into the water and let himself drown, but did not have the courage to do so, and ended up sitting on the bank, crying for himself and for his lot in life.

In contrast, here in the leper colony, when he walked up and down the village main road, people called his name and stopped him for a chat. He woke up in the leper colony, Grandpa Bảo added, to sympathetic people all around him: the nuns and his fellow inmates. His fellow inmates often affirmed to him, ‘Here we are all the same!’

Grandpa Thiện also came to Quy Hòa after several years of being contained in his house and enduring the pain of leprosy by himself. At the time, having given up hope for a cure after desperately seeking help from different traditional healers, he thought that he was the only one in the country suffering from this strange disease. However, as soon as he arrived in the leper colony, he was astonished to see so many people with the same disease; many of them even had more severe physical symptoms than him. Seeing many other leprosy patients with abnormal bodies was intimidating at first, but in retrospect, he reflected, it was also somehow reassuring for him to realise there were many others suffering from the same disease, and that he was not alone in his arduous struggle with leprosy.

Similarly, upon his arrival, Uncle Phương was surprised to see the leper colony already crowded with many inmates who had the same disease. Not only did they have the same kind of bodies — the same physical symptoms as him — but once he started mingling with other inmates, he was amazed at how similar their experiences had been before coming to Quy Hòa. He found that they shared the physical
pain caused by leprosy, and they had very similar experiences of being stigmatised, isolated or expelled from their communities of origin. Many felt deeply hurt by being shunned by their own family, banished by neighbours, excluded from the community, or even traumatised by a murder conspiracy aiming to eliminate the ‘leper’ peril. Here in the leper colony, people gradually found comfort and empathy in realising their shared pain as leprosy victims. Their ties, based on similar lived bodily experience and social reality of leprosy, were built and reinforced over time.

Uncle Phương, for instance, got to know a young lady called Sa in the leprosy village. At first, he was struck by her sad eyes. She had a very beautiful face, but her eyes were always clouded by sadness. When they talked, he was instantly touched by how similar their lives as leprosy sufferers were. She told him her life story, how she lost her legs because of leprosy, and mentioned many times that she was so despondent that she wanted only to die. He was struck by how her lived struggles were similar to his. Moreover, as a fellow amputee having to move around by wheelchair, he could understand profoundly the pain of losing one’s body parts. They felt close almost immediately and often shared their stories, despite the age gap of more than 20 years. They now are married and live happily together in Quy Hòa.

Many village men stressed that it is important to live with ‘the same’ people and to find a partner similar to them, particularly when it comes to marriage. Uncle Hùng, a former tailor, for example, was first admitted for a lengthy period of leprosy treatment in the Franciscan leper colony of Núi Sần, Nha Trang. In 1972, after being discharged, he lived outside for six eventful years. During those years, he joined the military of the American-backed southern regime and was relocated to Quy Nhơn with his regiment. More than once on their off-duty days, he recalled, his mates asked him to go for a brief visit to Quy Hòa leper colony, ‘because they had heard that lepers’ daughters are usually very beautiful’. However, he never agreed to go with them, since he was afraid people with leprosy in Quy Hòa would notice the marks on his body, which usually went unnoticed by people without experience of the disease. He was anxious that if the village inmates realised he also had leprosy, his secret about his past illness would be revealed.
After 1975, his family were among those relocated to the New Economic Zones under the new government’s policy. There he happened to bump into two men he had previously trained as apprentice tailors. They were delighted to see him again, but he insistently denied having known them. They affirmed, ‘You really look like our teacher, Hùng! You must be Teacher Hùng!’ and invited him to come to their house. Yet he kept shaking his head, ‘No, I am not Hùng!’ Uncle Hùng wistfully told me that, once he had been admitted for treatment of the disease, he did not want to meet any old acquaintances who had known him before then. He was worried they would ask him where he had been during their separation; he would then have to tell lies. ‘So many lies! I’m tired of telling lies’, he explained. Uncle Hùng concluded by telling me that it is much better to be with ‘similar’ people, so one can have peace of mind, and not have to tell lies or think twice before saying something lest one’s secret be revealed.

The turning point that catapulted Uncle Hùng back into an exclusive community for leprosy sufferers was a re-encounter with his ex-girlfriend, who had followed her family to settle down in the same New Economic Zone as Hùng. At first, he was happy to see her again and vaguely thought it might have been destiny that brought them back together. She was a gorgeous woman, ‘but had a cruel heart’, he reflected. After they had been casually dating for some time, she spread the news that he had leprosy among members of the youth association to which they both belonged. The rumours quickly spread through their neighbourhood. That night, as soon as he learned that his secret had been revealed, Hùng panicked, immediately packed his stuff, and ran out of the house. Now that people knew that he had leprosy, he dared not face anyone. The following day, he left the settlement well before sunrise so that no one could see him leave. Having nowhere to go, he decided to head for Quy Hòa, the village for leprosy sufferers he had known when his regiment was based in Quy Nhơn.

Uncle Hùng has remained in Quy Hòa, where, soon after he entered the leprosy village, he met his wife. He wanted to marry someone ‘like him’, he said, because he believed a wife who did not have this disease would look down upon (coi thương) him and his family and would not be loyal to him, causing his children to suffer.
After moving into the leprosy village, he rarely returned to visit his family. One of the few times he went back home was when his mother passed away. He arrived in time to attend the funeral, but he felt alienated outside his new community, surrounded by non-patient people. As the eldest son, he took on a major role in the funeral ritual. He was sitting, as was customary, in front of his parents’ house to receive guests, but most of the guests ignored him. Few people came to greet him, and those who did so only briefly said, ‘Oh you came back?’ or ‘Has your illness condition got better?’, and then quickly stepped away from him.

The other time was when he returned for a family reunion during Tết, the Vietnamese Lunar New Year. He went back one week before the New Year to help his father repair the ancestors’ grave, clean the house, and prepare for the rituals. Yet he eventually returned to Quy Hòa a few days before the New Year festival had started. Recalling that sad memory, he said he could not endure people’s comments and attitude towards him. Everywhere in the neighbourhood, people told each other, ‘that leper (thằng cụi) has come back!’ Wherever he went, people stared at him ‘in a weird way’, and when he came close to anyone, they walked away and avoided him. When people walked past his family’s house, they stared at him and whispered something to each other. He felt very sad and hurt, and decided to go away immediately, as he had done before. He had been looking forward to celebrating the Lunar New Year with all of his family for a long time, but he could not cope with people’s attitude towards him. In the end, he had a lonely Tết back in Quy Hòa, but as he reflected, he felt much better, safe and free here with ‘similar’ people.

For leprosy-afflicted people, ‘sameness’ is ontologically defined against difference. In other words, the importance of ‘sameness’ as lived and told by leprosy sufferers reflects the weight of ‘difference’ in their lived realities. Consistently enthusiastic emphasis of ‘sameness’ reveals a clear-cut dichotomy in the mind — a clearly demarcated territory of ‘people of the same kind’, those affected by the same disease, in opposition to the outside world. The notion of ‘sameness’ determines boundaries and clearly defines ‘patients’ (leprosy-affected people) (người bệnh/bệnh nhân) and ‘healthy people’ (người lành), ‘inside here’ (ở trong này) and ‘out in life’ or ‘out in the world’ (ở ngoài đời). James Staples similarly observes strong delineation between the ‘inside’ and the ‘outside’ perceived by people affected
by leprosy and living in an exclusive community in India (Staples 2004:77). Conversations with Quy Hòa residents are normally filled with anecdotes comparing and contrasting life inside and outside of the leprosy village. While ‘inside here’ signifies safety, security and familiarity, ‘out in life’ or ‘out in the world’ implies something intimidating, risky, and somehow other-worldly.

The Power of Sameness

Like Grandpa Thiện, Uncle Phước and Uncle Hùng, everyone I met in the village reported finding great spiritual strength and comfort in their ‘sameness’. Sameness itself has great power, as Bauman writes: ‘Knowing that one is not alone and that one’s own personal cravings are shared by others has a reassuring effect’ (Bauman 2001:63). In addition, community-living brings about the power of a collective and the comforting sense of belonging to a definite group. Community is a strategy to cope with the repercussion of stigmatisation, which Goffman refers to as ‘in-group alignment’ (Goffman 1963:112).

Quy Hòa reminds us of Robert Redfield’s ‘little community’: a distinctive, small and self-sufficient community defined by homogeneity and sameness (Redfield 1960). In villagers’ words and perception, Quy Hòa is first and foremost a community of sameness: a village ‘of the like-minded and the like-behaving; a community of sameness’ (Bauman 2001:64). Quy Hòa is where inmates can realise their commonalities in their illness and in past experiences, and thus, to borrow the words of Barry Adam (1978), commonalities are translated into a community that exists and lasts based on sameness.

For Grandpa Thiện, his body embodies shame; he always expressed honestly to me that he felt ashamed about his lacking body. Many times when we chatted, Grandpa Thiện stared fixedly at my fingers, thinking deeply about something. Whenever he happened to talk about fingers in our conversations, he always said ‘fingers, like yours’, as if he had never had them. For decades, it has been extremely rare for him to go out of Quy Hòa village. ‘I felt too ashamed to go. How could I wish to go out with limbs like this?’, he asked me, while slightly raising his deformed hands and glancing down at his toeless feet. He also never went back to his hometown because of fear that he would cause humiliation for his nieces and nephews:
Because they are my nieces and nephews, maybe they have no choice but to recognise me and call me their uncle no matter how they feel. But what would their husbands and wives think about me and our family? They would think this family has a leper uncle! They would despise [khinh] us, they would see my family as cheap [coi rể]. I would feel pity [tộì nghiệ] for my nieces and nephews if their spouses look down on them because of me. So I never want to go back anymore.

Aunt Khanh, too, was immensely saddened by the changes to her body caused by leprosy. Around one year after abandoning treatment because of her mother’s death, she was contacted by a nurse in the hospital who sent her a letter and advised her to come back in order to continue treatment, since there was a new type of therapy that had recently become available. In the period 1982–83, multi-drug therapy (MDT) was introduced to Vietnam, and leprosy patients were not only treated by a single type of antibiotics but by a combination of medicines, typically Dapsone, Rifampicine, and Clofazimine (World Health Organization 1998). With her family’s encouragement, Aunt Khanh returned to Huế for treatment.

As a side effect of MDT, patients’ skin can dramatically change colour to black or red during the period of treatment, and return to normal after stopping MDT. Aunt Khanh’s skin tone radically changed to a deep shade of black after taking Clofazimine (most often called ‘Lampren’ by leprosy patients). When her father came to see her, he was surprised, too, teasing her: ‘This dirty girl! Why are you as black as a smoked boiling pot?’

Multi-drug therapy was much more effective than the previous mono-drug therapy. Aunt Khanh was clinically free of leprosy bacteria after around one year of regular treatment. She now had the option of going back home or staying on to complete treatment until she fully recovered from the consequences of side effects. Looking at her body in the mirror, she found herself strange. Explaining her decision to remain in the hospital, she said:

It looks very weird to be as black as an African. I thought I would be as dark as this forever because of the medicine’s effect. I thought if I returned home, everyone would see that my face was as dark as a thickly burned pot [den nhut lọ nghe] and the neighbours would gossip about my skin. I looked so strange, like no one else [không giống ai]! So at last, I made up my mind to stay.
At the time, the leprosy section in the Huế dermatological department was cramped with too many patients. The hospital decided to relocate a number of patients to Quy Hòa, which was supposed to have more space and a better natural environment — fresh air, cool breeze and pristine beach, very suitable for medical treatment. Aunt Khanh was among those who were moved from Huế to Quy Hòa in the mid-1980s, and she has remained there until now.

There was a point in time in the early 1990s when Aunt Khanh and her husband came very close to leaving the exclusive village and moving out to reunite with his sister. Aunt Khanh had met and fallen in love with her husband in Huế hospital. They married very soon after she arrived in Quy Hòa, where he lived. His sister, who was living and working in a state-run plantation (nông trườn), insisted that the couple should come and join her, since at the time the plantation needed more people and they would be able to do farming on the plantation’s huge area of land. The sister thought that it would be an ideal opportunity for them to reunite, because the plantation could offer land, work, and housing.

It was indeed a reasonable plan and Aunt Khanh seriously considered joining the plantation. By that time, she had already finished treatment; her skin tone had returned to normal and she did not have any explicit leprosy residues. However, her husband was very reluctant. He had an amputated leg, but, as they discussed, people might just think that he was a war invalid who had lost his leg during the war. What made him hesitate were some ulcers on his hands, which had deteriorated due to his work as a carpenter, making wooden furniture for the leprosy hospital and villagers. The hard work with saw, knife, hammer, and nails had affected his numb hands and exacerbated his hand injuries. Moreover, he felt uneasy and anxious about co-living in a shared house (nhà tập thể), the only accommodation option provided by the plantation, where they would live in very close proximity with and share common facilities with other workers’ families. He was scared that the injuries would sooner or later reveal their secret; the neighbours would notice his wounds and realise he was a leprosy sufferer, and they would have to escape in humiliation. Eventually, he decided to reject his sister’s offer and stayed on in Quy Hòa, rather than going out into the world with the risk of becoming known as ‘lepers’.
Although their decisions to remain in an exclusive environment for leprosy sufferers took place at different points in time, both Aunt Khanh and her husband decided to do so because of their concern about bodily difference. For Aunt Khanh, her husband, and many village residents, the multiplicity of similarly defective bodies inside the community has a deeply reassuring effect. ‘Community means sameness, while “sameness” means the absence of the Other’, writes Bauman (2001:115). Inside their own world of sameness, community members do not have to worry about their difference or being seen as abnormal. Discussing life in leprosaria for Japanese leprosy-afflicted inmates, Susan Burns writes, ‘for leprosy sufferers themselves, sites such as Yu no Zawa, offered up the hope of a “normal” life within the culture of exclusion, a life in which work, family and community might be possible’ (Burns 2003:117). Within this distinct territory, and amid hundreds of ‘people of the same kind’, abnormalities are evened out and can be normalised; lacking bodies become normal, and illness becomes a matter-of-fact, albeit an important one. Village residents can enjoy the benefit of such a ‘normalising’ environment, as termed by Kelleher (1988).

For instance, the village men told me it is only in Quy Hòa where they could walk around freely without tops, as Vietnamese men usually do, particularly under the sweltering tropical sun. Outside the village, they would never be able to do so; when some villagers go back home for a visit, they do not even want to be seen by neighbours, let alone reveal their scarred and lacking bodies. Uncle Nghị told me that while he was still living with his family, his neighbours did not explicitly shun him. He remained mainly in the house without stepping outside. Yet he felt the occasional intrusive gazes, and the concerned stares from his neighbours through the small window were intrusive and unsettling enough for him to decide to leave his family for Quy Hòa. ‘It is free [tự do] here. I don’t have to worry about such things’, he commented. Now in the leprosy village, he can bare his torso and limbs marred with scars to work all day under the sun at his little bicycle repair shop in front of his house.

My own introduction to the practical meanings for villagers of physical sameness and the tacit value they attach to being among people like themselves came when I first went to pay respects to Grandpa Thiện, who was to become one of my main interlocutors. He was among the first villagers I met in Quy Hòa because his house was the first near the
village gate on the main road connecting the hospital and the village. Every day when I walked into the village, I had to pass by his little house.

When he first came to Quy Hòa, Grandpa Thiên was hopeful that his treatment would be finished soon so he could go back home. Yet it was when his body became deformed because of leprosy that he painfully realised that he could never return home. Moreover, during the tough years after 1975, his limbs were ruined further because of the hard labour of collecting firewood and burning it into charcoal on the mountain near Quy Hòa. Grandpa Thiên felt profoundly humiliated because of his deformities, the leprosy ‘marks’ fixedly remaining on his body would signal his disease wherever he went.

Grandpa Thiên’s limbs, indeed, are badly deformed from leprosy and the hard labour that took its toll on his already damaged body. Many of his fingers and toes had already been amputated either completely or by half, while the remaining half fingers and toes became hard and crooked. Most of the time his truncated hands were black with soil and dirt, since every day he fed the chickens and went out to search for fallen coconut fronds on the ground, cut them into small pieces, and dragged them back home for his wife to burn for cooking.

On one of my first afternoons at Grandpa Thiên’s house, I brought him a cup of sweetened iced coffee, bought from a café in front of the hospital. It was a takeaway coffee in a thin, transparent plastic cup that could be thrown away after use. To my embarrassment, Grandpa Thiên confusedly tried different ways to hold the plastic cup with his half-amputated fingers. The plastic cups used for takeaway by this café were not good ones; they were too thin and soft. After trying to pick it up for a while with no results, Grandpa Thiên stopped and left the coffee cup where it was on the table. He seemed embarrassed and there was an awkward moment during which neither of us said anything. Fortunately, we found a way to recover from my gaffe and restart the conversation. To this day, I recall the gulf that my gift had suddenly opened up between me and my elderly respondent. Thinking back to the proverb Grandpa Thiên once shared with me, at that moment I was indeed a duck out of place among the chickens.
4. ‘HERE, EVERYONE IS LIKE EVERYONE ELSE!’

After that intensely awkward beginning, I went on to develop a warm and sustained relationship with Grandpa Thiên. I would frequently go and sit with him in the slanting sun of the late afternoon on the porch of his little house. We talked about his life as he tended his chirpy chicks. I still brought him some snacks or drinks, such as soy milk packets, which, as I worked out, he could handle with his fingers.

Ferdinand Tonnies, cited in Zygmunt Bauman (2001), observes that modern community is defined by ‘an understanding shared by all its members’:

> The community-style, matter-of-fact … understanding does not need to be sought, let alone laboriously built or fought for: that understanding ‘is there’, ready-made and ready to use — so that we understand each other ‘without words’ and never need to ask, apprehensively, ‘what do you mean?’ (Bauman, 2001:10).

The sense of physical ease and naturalness provided by this condition of mutual acceptance and tacit understanding is all the more palpable in the context of Quy Hòa village as a congregation of people with bodies that inevitably attract attention in the wider society as abnormal or defective. In the atmosphere of the village, one can be oneself, for it is there that such bodily differences are tacitly understood to be normal.

**Conclusion**

While leprosy stigma in the wider society is slow to change and medical science can offer an only incomplete cure — a biomedical therapy that is highly effective but unable to reverse disfiguration or remove social pain — leprosy-afflicted people continue to fashion a therapeutic life world for themselves in the form of exclusive residential communities such as Quy Hòa. Such leprosy villages constitute a healing environment defined by sameness and equality. Into this world come those experiencing the pain and sadness of ‘social death’ and a ‘spoiled identity’ (Goffman 1963), and those who wish to withdraw socially or become invisible to the world of physically intact people. Yet within this life-reinforcing exclusive territory for ‘lepers’, they are reborn, re-empowered, and revitalised; they are able to express themselves freely as human beings, dignified and equal with everyone else.
Heide Poestges (2011) observes that in the exclusive leper colony in India where she conducted research, members use stigma as a mechanism to create and maintain community membership, and as a strategy to mitigate various social problems induced by their disease. In a related vein, this chapter holds that, ultimately, leprosy-affected people’s profound desire for equality and dignity lies at the core of their need for an exclusive social world. The outside society may deny them complete personhood and full dignity as equal human beings; yet they can find comfort and a ‘normal’ life with a community of people ‘of the same kind’. Whereas their leprosy-ruined bodies are feared and reviled outside the village, inside this exclusive territory they return to being normal and equal to other villagers. Sameness in its physical and social aspects constitutes the main healing effect of this community, which offers a comforting and reassuring environment that nurtures social interactions, relationships, and mutual support.

Crossing the border between their village and the outside world, people affected by leprosy continue to realise palpably the difference in their social standing in the two spheres. The curiosity, fear and discomfort occasioned by their presence ‘out in life’ hurts, but it also reinforces the abundant appreciation for their place ‘inside here’. For many, the discomfort engendered by such forays into the world overlays the traumatic memories of exclusion experienced when they first contracted the disease and corroborates the potent sense of their community as a unique sanctuary. It is for these reasons that leprosy villages such as Quy Hòa still exist with great vitality. Residents genuinely cherish the exclusiveness, which also means sameness, of their communities. Susan Burns has similarly noted that Japanese leprosy sufferers embrace the culture of their own exclusion (Burns 2003:116). Writing about leprosy in India, James Staples reflected: ‘While ill health might unmake the sufferer’s world, in certain contexts — like this one — it also remakes it’ (Staples 2003:308).

Quy Hòa is intimately appreciated as ‘home’, as a shelter, and as a place of rebirth and revitalisation where people can hope to find again things taken away from them by this cruel illness: dignity, faith, hope, care, love, peace, friends, family, and future. Exclusive communities offer a social cure that brings back what sustains a meaningful and fulfilled life. Leprosy villages such as Quy Hòa can heal because they cure the most intrinsic pain of leprosy.
References


Leerapun, P. 1989, Health-seeking Behaviour of Leprosy Patients in Northern Thailand, Mahidol University, Faculty of Social Sciences and Humanities, Thailand (in Thai).


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