Leprosy, the key to another kingdom

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Summary
Objective: In India, many people affected by leprosy still live in self-established settlements, commonly referred to as leprosy colonies. Aid organisations generally attribute the social segregation of colony members to the stigma attached to leprosy. In this article, I argue that the common approach towards leprosy colonies is actually based on a limited understanding of social relations between colony members and others. The insights from this study will hopefully facilitate re-thinking current approaches to stigma reduction in leprosy.

Design: An ethnographic study conducted over a period of three months in and around a leprosy colony in India. With the help of a local research assistant, I carried out semi-structured interviews, informal conversations, and participant as well as non-participant observation. I conducted interviews with 22 colony members and 25 residents from the adjacent neighbourhoods of the colony.

Results: This study reveals that the differentiation between colony members and others derived at least as much from community membership as from stigma. Leprosy-affected people living outside the colony, for example, perceived the colony members as widely different from themselves, whilst stigma affected both groups. Programmes with the aim of reducing stigma need to approach stigma relations as embedded in various interrelated physio-emotional and socio-cultural processes, rather than approaching social aspects of leprosy by focusing exclusively on the notion of stigma.

Introduction

Leprosy is an infectious disease in which involvement of the skin and nerves may, untreated, lead to loss of sensation, blindness and deformities. In the literature as well as in the circles of development aid workers, leprosy has been conceptualised as a metaphor for stigma.
Despite all efforts to rehabilitate leprosy-affected people, many self-established settlements, commonly referred to as leprosy colonies, still exist in India. The exact number of such settlements is unknown. The Sasakawa Foundation, however, identified more than 630 leprosy colonies and the real number was even estimated to be higher.\(^2\) Aid organisations commonly attribute the social segregation of colony members to the stigma of leprosy. For this reason, the re-integration of colony members into society is a common desired objective of interventions with the aim of reducing stigma. Drawing on ethnographic fieldwork conducted over a period of three months, this article offers a different thesis which suggests that the social identity of colony members derives at least as much from group membership as from stigma.

In particular, I argue that stigma was used as one of many mechanisms by colony members and non-affected people to create and maintain community ties; stigma and community membership in the colony are, therefore, related but they are not identical. Consequently, this paper emphasises that stigma relations need to be understood as part of multiple interrelated physio-emotional and socio-cultural processes. The insights from this study will hopefully facilitate re-thinking current approaches to stigma reduction in leprosy.

I begin this article with a critical discussion about common stigma concepts followed by a summary of the approach I have taken. After a brief description of the methodology and study area, I go on to explore perceptions of a leprosy colony from the perspective of both the colony members and people living in the adjacent neighbourhoods of the colony. Towards the end of my explorations, I highlight the different perceptions between colony members and leprosy-affected people living outside the colony. Finally, I complete this article with a critical discussion and conclusion.

**Defining Stigma**

Social psychologists commonly approach stigma processes as emotional responses to socially constructed labels and stereotypes.\(^3\) They view the effects of stigma as located within the stigmatised person. Most papers refer to Goffman’s\(^4\) definition of stigma as ‘an attribute that is deeply discrediting’, and that reduces the bearer ‘from a whole and usual person to a tainted, discounted one’.

Goffman’s approach towards stigma, nevertheless, was rather social than individualistic.\(^5\) In Goffman’s view stigma manifests in a new social identity which is based on categories that are constructed in face-to-face interactions. He deliberately shifted the notion of stigma from symbols to social processes and was aware of unequal power relations.\(^6\)

In order to broaden the individualistic focus of psychological stigma concepts, Link and Phelan\(^7\) provided a definition of stigma that combines elements of different stigma models. Some elements are similar to the psychological models and include labelling, stereotyping, and cognitive separation. Their definition additionally covers status loss and discrimination, and emphasises that stigma processes can only take place by an unequal distribution of social, economic and political power.

Others further argue that decisions to stigmatise are limited by already existing social structures and do not take place exclusively on the interpersonal level.\(^8\) Graham Scambler\(^6\) criticises Goffman for giving insufficient attention to how social interactions are embedded and reflected in social structures such as class, command, status, gender and ethnicity, adding that also Link and Phelan’s definition only lightly touches the topic. Inside the leprosy colony that I studied, I noticed, for example, an especially pronounced consciousness of hygiene.
The entire area was very well cared for and clean compared to other neighbourhoods. One leprosy-affected woman told me: ‘We feel that we are cleaner and much more hygienic than people from other places.’ Quite likely this significance of cleanliness was related to Hindu notions of purity. Put very simply, Hindu caste, at least as represented by Brahman scholars at the top of the hierarchy, is a system of social differences according to people’s relative purity. Those from the lower castes, within this logic, are seen as relatively impure and, as a consequence, they can soil higher castes. Although the reactions towards leprosy were rather ambivalent than exclusively stigmatising over the course of many centuries, the social status of leprosy-affected people has mostly been low. In official Indian discourses, leprosy affected people have consequently been classified as impure and they have sometimes been called ‘untouchables’. The leprosy-affected colony inhabitants, I would argue, attempted to counteract this classification by placing great importance on literal cleanliness. These findings emphasise that current stigma relations need to be understood as interrelated with various already existing social categories.

Those who are stigmatised and those who stigmatise are, nevertheless, not just positioned differently according to structures of stigma; they also inhabit shared social space. ‘They are bound together in getting things done, in the practice of addressing illness and stigma.’ Sociological concepts, however, fail to overcome the binary distinction between those stigmatising and those who are stigmatised. For the purpose of this article, then, I define stigma ethnographically. Yang et al. approach stigma by focusing on ‘moral experience’ which refers to feelings of ‘practical engagement that defines what matters most for ordinary men and women’ in everyday life. According to them, ‘both the stigmatizers and the stigmatized are engaged in a similar process of gripping and being gripped by life, holding onto something, preserving what matters, and warding off danger’. Stigma is consequently defined as a process that put at risk ‘what is most at stake, or actually diminishes or destroys that lived value’. During health-related stigma processes, bodily states are linked with experiences of emotions and social values which are in turn inter-dependent. Since both the stigmatiser and the stigmatised are involved, these processes occur in the inter-subjective space between people. In this space, stigma is displayed in everyday forms of social interactions. Rather than elaborating on structural categories as such, the focus of this article is, therefore, on how existing categories are re-produced and counteracted through everyday practices by all stakeholders involved. In addition, my analysis is not limited to a binary distinction between the colony members as the stigmatised and those who stigmatise them but rather brings together vantage points of different stakeholders involved.

It must, however, be noted that this study covers only a small part of various experiences related to stigma. Exploring other or additional processes would have revealed another part of the picture. The focus on at least some examples of practical engagements and interpersonal danger can, however, deepen the sociological understanding of the role that stigma plays in everyday life.

Methodology

My analysis draws on data produced during an ethnographic field study, which I conducted from August to November 2006 in and around a leprosy colony in India. I collected the data using semi-structured interviews, informal conversations, and participant as well as non-participant observation of three different groups of informants. The first category represented
colony inhabitants, of whom I investigated 12 people with impairments and 10 of their relatives. The second category included 14 inhabitants of the adjacent neighbourhoods, in whose families no leprosy had occurred. The third category comprised 11 leprosy-affected people who had settled down in the neighbourhoods outside the colony. The interviews were conducted in and in front of the informants’ homes with the help of a local research assistant. The interviews were tape-recorded in Tamil, and later translated and transcribed into English. The data were analysed using ethnographic methods.

THE LEPROSY COLONY AND ITS ADJACENT NEIGHBOURHOOD

The study area consisted of the leprosy colony and the streets that ran immediately around it. The colony and its adjacent neighbourhoods were situated just outside a small town. All in all it was obvious that, in my study area, there was an above-average presence of leprosy in the streets compared to most other rural as well as urban areas in this region. This can be attributed to the existence of a hospital that was once specialised in treating leprosy. Many of the former patients of the hospital settled down in the area after completing their treatment. The hospital was situated on one busy street. From this road diverted narrow, unpaved lanes, which led to the leprosy colony and the homes of my other informants.

The leprosy colony

The houses of the colony made up a small village in themselves. Yet the area of the colony was neither fenced nor walled off. On one side of the colony, a rocky hill created a natural border. At first glance, the place was indistinguishable from other areas. The area was, however, remarkably clean, pleasantly quiet and featured virgin forest. The colony consisted of 100 stone houses and three huts. Half of the houses were built either by the state or by non-governmental organisations. All houses had electricity, yet no running water. There was also a church, a temple, and a community hall, donated by Christian and Hindu religious communities from around the region. The colony could be considered a fairly typical of Indian leprosy colonies, based on its housing and living standards.13 Housing there was, in fact, of a higher standard than that of the poorest families in the neighbouring areas.

The colony had a total of 360 residents.14 Of the adults, 111 had impairments that could be attributed to leprosy. Further residents included a blind man and a deaf-mute woman, who were ostracised by their families. Nearly all of the physically impaired residents were professional beggars, which meant that they would spend the majority of the week and public holidays in a city 100 kilometres away from the colony. The residents without disabilities were the children and grandchildren of people with disabilities. None were engaged in professional begging.

The settlers’ initial answer to questions about the reasons for settling in the colony was that returning to their families would have had negative consequences for the family members. On the other hand, during in-depth interviews, it emerged that only a relatively small contingent of leprosy-affected people had been ostracised by their families. Some named the marriage with a leprosy-affected person who belonged to a different caste as a reason to not be able to return to their hometowns. The majority of the residents had also converted to Christianity during the course of their illness, which further hampered the possibility of returning. Many of the settlers had previously lived in a colony in a city nearby, which was disbanded by the state due to the construction of a new road. Others had come after living at other places for years, or after long periods of hospitalisation and losing contact with
relatives. Again others had joined the colony only after their spouse had deceased or after their physical condition had rapidly deteriorated.

The adjacent neighbourhood

The closer the streets were to the hospital, the more leprosy-affected people lived next to families unaffected by the disease. Here, the leprosy-affected people I spoke to had their own houses and steady jobs. All of them settled down in this area after completing their treatment in the hospital between 20 and 40 years ago. The reasons for not returning to the places where they originally came from varied. Some stated that they were ostracised by their families or communities, others stayed because they had found a marriage partner during the period of hospitalisation, and for still others the job opportunities were better here. None of them had ever considered settling down in a leprosy colony.

Another paved side street led to a nursing home for leprosy-affected people, the residents of which I interviewed as well. There were 11 permanent residents. About 20 others came from places nearby and had found shelter only for a limited time. Up to a certain age, these people had lived with their families and participated in the life outside of institutions for those affected by leprosy. Women mostly specified the death of their husbands and their deteriorating physical condition as the reasons for their admission. Men mostly cited their physical condition and reduced marriage opportunities for their grandchildren as the main reasons.

The informants in whose families no leprosy had occurred lived in side streets a little further away from the hospital and the colony. All, except one woman, were locals who had lived in the area all their life.

Results

STIGMA IN AND AROUND THE LEPROSY COLONY

Different authors have described various sources of the negative attitudes towards leprosy and the reasons for its persistence over the years.1 The most common notion of stigma, however, still refers to people’s fear of mingling with leprosy-affected people, due to a lack of scientific knowledge and suspicious ideas about the disease. My approach towards stigma, however, reveals various additional factors that influence attitudes related to leprosy.

Most people living in and around the leprosy colony perceived strong bonds with family and community members as very important in their lives. One effect of leprosy-related stigma was to weaken or even destroy these very family and community ties, which made people experience leprosy as so dangerous. In our conversations, colony members repeatedly emphasised, for instance, how painful it had been for them to have been forced to leave their families due to their disease; and leprosy-affected people living in the adjacent neighbourhoods told me, for example, about their difficulties to find a marriage partner.

Stigma was, however, not only a perceived and real danger for the people affected by leprosy but also for their family members. Some of the leprosy-affected people mentioned that they left their families because the chances for their relatives to find a spouse would have decreased otherwise. This shows how stigma can threaten the social life of an entire family.

The fear of leprosy-affected people and their families of losing what they perceive as most important in their lives was in addition also felt by others who were not stigmatised. In the community around the colony, those who lived away from their families were, for instance,
generally understood to be unhappy. Yang et al. have already pointed out, though in the context of mental illness in China, that people may respond to such a threat by discriminating and marginalising others. Also the majority of residents around the colony without a family history of leprosy would have neither shared food with the leprosy-affected nor wished for amicable contact. When I showed a photograph depicting a leprosy-affected woman with clearly visible deformities on hands and toes embracing me, one of the viewers – a well-situated middle-aged lady who had moved to this neighbourhood only two years ago – shook her head in disgust. None of the non-affected locals living around the colony showed such a strong reaction though. Nevertheless, the vast majority of non-leprosy affected inhabitants of the neighbourhoods outside the colony refused to agree to the marriage of a leprosy-affected person to one of their family members.

To sum up, in and around the leprosy colony, the impact of leprosy-related stigma manifested itself partially in social exclusion. People perceived strong family and community ties as one of the most valued things in life. Those who were not affected by leprosy had the power to protect their own ties by threatening the ties of those affected by leprosy through, for example, preventing marriage opportunities.

Narratives about the Origin of the Colony

Most of the community members living in the adjacent neighbourhood, who were not affected by leprosy themselves or through a family member, knew that the surroundings of the hospital were a settlement area for former leprosy patients. A distinctive characteristic of the area was the hill. An old man told me: “The hospital was built at this particular place because there is a hill. Inside the hill, there is some remedy for this kind of disease.” Building my approach on what Daniel described as the significance of place to identity, I would suggest that these narratives were, at least in part, figurative. The hill was perceived as an outstanding geographic characteristic of the area and served to emphasise the differentness of the people who lived there. Staples described in his study on the leprosy colony in Andhra Pradesh that stories about the existence of evil spirits in the region fulfilled the same purpose.

The residents of the colony were further regarded as belonging to a different group of people as they had moved to the area from elsewhere. Members of the founding generation of the colony were born around 200 to 300 kilometres away from this area. According to the members of the local population, the leprosy-affected people and their offspring would therefore always remain strangers in this region. As newcomers they were denied membership of the local community, which further threatened their family and community ties.

Creating and Maintaining Community Membership

In his illuminating ethnography, James Staples already challenged the widely held perception that reduces people affected by leprosy to powerless victims of the most degrading disease. In this section, I show that the colony members had developed their own strategy to cope with the threat to their social bonds. They namely responded with the development of a very strong community membership that provided access to their own social world, in which they had the power over social inclusion and exclusion. I demonstrate how stigma was used as a mechanism to create and maintain this group membership by colony inhabitants, and how this process was inter-related with how they were perceived by others from outside the colony.
The concept of a collective leprosy-affected body

The first settlers relocated to the colony from various regions and also their religious and social backgrounds differed greatly. What they all had in common though was that they had once been institutionalised as leprosy-affected people. Collective conceptualisations of leprosy and the leprosy-affected body were therefore critical for sustaining a sense of community in the colony.

On the surface, the colony represented itself as a collective leprosy-affected body, also encompassing colony inhabitants without a personal history of the disease. This became obvious already during my first visit. It was a Wednesday night, during which most of the afflicted residents stayed in a city nearby to beg. The rehabilitation manager, who helped me to get access to the colony, knew some of the residents and wanted to introduce me to them. He asked specifically for the leprosy-affected people of the colony. A woman without visible consequences of a leprosy infection retorted: “Who do you mean? We have all leprosy!” As later conversations with colony residents yielded, this concept of the collective body derived from the discrimination that the entire family had to face. They explained to me: “It is a disease through which the whole family gets neglected. We have the same trouble as our parents, although we are healthy children.” The reason for this suffering lay, according to the residents, in the loss of desirable conditions such as being independent, wealthy and educated; qualities they found typical for the population outside the colony. To be leprosy-affected, however, meant to be exposed to the suffering of the illness, which denied them wealth and education. This collective role as sufferers, regardless of a personal history of leprosy, helped the colony members to maintain a sense of community.

Stigma as a means of fundraising

Also according to the view point of non-affected inhabitants of the adjacent neighbourhoods, the leprosy-affected body represented a key symbol for all colony inhabitants. Their descriptions of the consequences of leprosy were, however, restricted to visible corollaries of the disease. For instance, one man explained: “By looking at them [the colony inhabitants] you can say that they are leprosy patients.” The deformities caused by leprosy were perceived as degrading people’s social status to sufferers who are in need of help. The colony members made use of this stigmatising image of a leprosy-affected body in order to cope with other negative effects of leprosy. This image helped colony members to justify their right to receive compensation for the pain they had suffered. They collectively voiced their particular rights to state-funded support, as well as help from private organisations and people. The colony members consequently regarded begging as a legitimate source of income. For example, one resident stated:

“Because of our deformities caused by the disease we can’t work. We can’t do other work than begging. [...] We are also unable to do work like teaching, which can be done with physical deformities. The reason is that none of the affected people is educated. In earlier days, when our disease started, we were neglected and ill-treated. And we were also not allowed to acquire good education.”

All informants stated that they did not beg voluntarily but due to a lack of alternatives. At the same time, the majority of them rejected loans for setting up ‘micro-economic’
enterprises offered by aid organisations. Most residents did not regard it as an alternative to begging. They ensured repeatedly that their physical condition was too bad to work and that such enterprises were not financially viable. Through begging they did not only cover their basic needs, but, for example, also the education of their children. In so doing, they tried to ensure for their children the education that they themselves had always been denied. They reported proudly the good marks of their children. The education of their children contributed noticeably to the increase of their self-esteem. Or as Staples\textsuperscript{18} formulated it: ‘the money raised from begging [...] does bring dignity to those who have acquired it.’

These developments in the colony lead to ambivalent reactions of the inhabitants of the adjacent neighbourhoods. They were surprised about the healthy appearance of the children of the colony members. While I was interviewing them, some women resentfully accepted that some children from the leprosy colony were better students than their own. Another woman added that it was impossible to notice in the children that their parents had leprosy. They would often look healthier, better nourished and more hygienic than their own children. Judging by their gestures and tone of voice, the women also seemed jealous of those from the colony. This jealousy reached beyond the academic achievements of their children to the economic situation of the colony inhabitants. Throughout the discussion it was again and again emphasised that leprosy-affected people were supported by foreign organisations, and that nobody had as yet supported them. The non-leprosy-affected people therefore disassociated themselves from the people affected by leprosy based on both stigmatising ideas about leprosy and the achievements of the colony members through utilising stigma as a means of fundraising.

Distinctive social values within the colony

The colony members had developed their own social values that varied significantly from those outside the colony. The residents perceived the colony as a better world compared to the outside environment. Here, they felt at home and cared for within a good social environment. One of the older residents told me:

“I have a very happy life here. I don’t feel like going back to my relatives because they neglected me when I was a child. The people in the colony are more important to me than anybody else.”

Even most of the children of the former leprosy patients have so far returned to the colony after staying in hostels closer to their schools. Most of them were married either to others from their colony or to members from other leprosy colonies. They did not want to leave their parents, who increasingly needed help as they aged. A young father of three children explained to us:

“Today we can work hard and earn money. But it doesn’t mean that we should leave our parents. See, my mother is a leprosy patient. When I was little, she took care of me for such a long time. Now, I am grown up and nobody on earth can take better care for my mother than I. The second reason is that I am working in the chicken centre. I am earning enough. My wife and our children are healthy. I am healthy, too. My children study. The house is our own. When all the facilities are there and we are provided with everything we need, why should we leave the colony?”
The residents also announced that they were more socially and religiously educated than the population outside. Solidarity was a key symbol. Their superiority in terms of solidarity was expressed through the equal treatment everybody received in the colony. They emphasised that the inner values of a person were more important than among people in the neighbourhoods. Through my observations, I can confirm a difference in social values. Right in the beginning of my field work, I noticed that women played a different role than in the adjacent neighbourhoods. On most days, some colony members gathered for discussion on the covered forecourt of the temple. They discussed matters concerning their community. It was noticeable that women and men sat interspersed. In gatherings of this kind outside of the colony, I usually observed men sitting on one side and women on the other. Inside the colony, women discussed, gestured, and were at least as engaged as men, who listened respectfully. Just as in the leprosy colony that Staples studied, the residents also drew no difference between people from different castes and religious denominations. One of the statements regarding this subject was:

“After the death of my first wife, I came to the colony with my son. I am Muslim and my second wife is a Christian. She has brought up my son. I don’t care about her religion. It doesn’t mean anything to me. She is a good wife to me and she was a good mother to my son. It doesn’t bother me that she is a Christian. We are definitely very happy together. I don’t care for castes or religiousness.”

Religion, however, played an important role in the lives of the colony residents. A small proportion of the colony inhabitants consisted of Hindus and Muslims. The majority, however, had converted to Christianity during their sojourns in Christian hospitals. Every Monday, a service was held in their church. Some residents regularly visited churches outside the colony, as the community lacked a priest and no full mass was performed. A young female resident told me that she had visited a neighbouring church a few times, and that she had participated in Bible lessons, which always ended with a quiz about the Bible’s contents. She said she always won, as she was better educated than the Christians outside the colony. She perceived these Christians as bad company for her and her family and therefore ended her church visits. Here, as well as in the descriptions about the value of solidarity and hygiene, it becomes evident that within the colony, a particular cultural milieu, with its own norms and values, had emerged. The religious denominations of the inhabitants of the neighbourhood were, for instance, vastly different, as the majority were Hindu. Most of the people outside the colony regarded it also as problematic to intermarry between different castes and religious beliefs. The culture in the colony was hence substantially different from that outside, and aggravated the social interaction between both groups. The social affiliation with the colony had become a fundamental part of the colony members’ self-perception. It is, therefore, unrealistic to believe that this worldview could be changed within a short time, as the residents had internalised it as part of their own cultural and social values. The integration of colony inhabitants into the broader society would therefore be neither possible nor desired on behalf of the residents in the near future.

Control over community membership

Staples equally arrives at the result that colony inhabitants create their own world as a solution to their problems stemming from leprosy. He refers to van Dongen’s thesis, that:
‘To constitute a social world of their own – a social world within which they can live in peace – is more important than is the modern obsession with promoting autonomy and independence’. This assertion, which van Dongen made in relation to institutions for seniors and psychiatric patients, also applied to the residents of this colony. The colony members were not interested in individual autonomy and independence but primarily in the creation and maintenance of their own social world. The residents repeated over and over again: “The colony is our kingdom. Here we are the kings.” Using the image of kings, the colony members emphasised that, within the colony, the people with disabilities had the power to decide which persons they would include and who they would exclude from their community. For this purpose, they founded a Panchayat, which was, however, not officially recognised as a local self-government by the Indian government. This Panchayat consisted of a president, a vice president and a secretary. Colony residents re-elected the committee every three years. Nominees were principally only residents with disabilities, although it was irrelevant whether the disabilities originated from leprosy or other causes. Those who wanted to relocate to the colony had to apply to the Panchayat, and everybody without disabilities or a family background in leprosy was denied a life in the colony. Controlling the membership in their self-established community enabled the colony members to reduce the threat to weaken and destroy their family and community ties. As a reaction to the social exclusion imposed from outside, the colony inhabitants hence created and maintained their own community membership and made their contribution to the segregation of the colony.

Leprosy versus colony member identity

Leprosy-affected people living in the adjacent neighbourhood disassociated themselves from the colony members. They adhered to traditional values and cited bad morale inside the colony as one of the key characteristics of the residents. Marriages between different castes and religious denominations as well as cohabitation without a marriage certificate were perceived as immoral. They also judged colony residents as demanding, professional beggars, for whom begging was the only source of income. In our conversations, they made immediately clear to me that they are different from the colony members as they have never begged before and will never do it in future either. One old man said to me:

“The money matters there [in the colony]. They want to earn somehow. Even begging is one of their sources. But people here [in the elderly home] don’t prefer to beg because we are given all the three meals and we got at least certain facilities. And that is more than enough. I don’t want to be like them because I don’t like begging.”

Leprosy-affected people from outside the colony regarded themselves rather as modest workers. Whilst they had developed similar deformities as the leprosy-affected colony members, most of them had a regular job or had worked at least up to a certain age.

On the other hand, they also saw the colony residents as living in their own, more liberated and dignified world. They had observed the cars of national and international aid agencies travelling to the colony in order to support its members through donations. This caused jealousy, through which the negative attitude towards the population of the colony was amplified. The leprosy-affected people outside perceived themselves as the oppressed,
who were deprived of their dignity not only due to leprosy but also due to being abandoned by aid organisations.

Through the comparison of leprosy-affected people living in and outside the colony it becomes clear that belonging to the group of colony members means more than just living with the physical and social consequences of a particular medical condition. Leprosy-affected residents of the surrounding area perceived themselves as fundamentally different from the colony inhabitants, although people from both groups have been afflicted with the disease in the same way. Although they would have had access to the colony, they could not identify with the colony members due to their different moral values. Contrary to the colony residents the leprosy-affected people in the adjacent neighbourhood considered themselves as members of the broader local community. However, they were aware that many non-affected people did not share their ideas of unity. Their possibilities were therefore generally limited to hiding their deformities in the hope of presenting themselves as people without leprosy or, at the very least, to counteracting the image of being passive victims. In interactions with aid organisations and while begging on the streets, the colony members, on the other hand, presented themselves as sufferers of a stigmatising disease in order to justify their need for financial support. The portrayal of passive victims, perpetuated on behalf of the colony residents, posed a threat to the existence of leprosy-affected people outside the colony, as this would keep negative associations with leprosy alive and further complicated their situation. They hence experienced the existence of the leprosy colony and the attitudes of colony members as a threat to their own existence. For this reason, they rejected the amalgamation with leprosy-affected people inside the colony, which shows that leprosy identity was not identical with colony member identity. It further demonstrates how group membership was different from leprosy-related stigma. The leprosy-affected people living outside the colony perceived the colony members as widely different from themselves, whilst stigma affected both groups. Although both lacked power to compete against the social structures, in which the leprosy-related stigma has been embedded, they developed strategies to cope with the negative effects of stigma. The strategies of the two groups were, however, contesting. One group tried to conceal that they were affected by leprosy in order to escape from negative effects of stigma, whilst the other utilised the stigmatising image of a leprosy-affected body to counteract the negative effects. Stigma and community membership of the colony were therefore related but not identical.

Discussion and conclusion

Those who were not affected by leprosy had the power to weaken or even destroy family and community ties of the leprosy-affected people through stigmatisation. These ties were, however, not only threatened by the effects of the stigma attached to leprosy. Non-affected residents considered leprosy-affected people and their offspring also as strangers in this area, and therefore denied them membership of the local community. This paper emphasises that the colony members developed their own strategies to cope with these social challenges by using stigma as one mechanism to create and maintain community membership in the colony. Since the first settlers of the colony had different religious and social backgrounds and came from various regions, they had not much in common except that they were once institutionalised as leprosy-affected people. In order to sustain a sense of community in the colony, colony inhabitants identified themselves as leprosy-affected. They also coped with
other negative effects of stigma through applying the image of a stigmatising body during fund raising activities.

The colony members have further created their own social world in order to overcome social challenges. As a consequence, being a member of the colony had become a fundamental part of the self-perception of inhabitants, which had even affected members of future generations without having ever been afflicted with the disease themselves. Since members of the colony had internalised their own cultural values, it is unrealistic to believe that this worldview could be changed in the short term. Moreover, they actively contributed to their segregation by excluding others from their community. In so doing, they maintained a very strong community membership that separated them from the broader community. Whilst their segregation was partially caused by oppression, it was hence at the same time a strategy to counteract this power.

The colony members as well as people from the surrounding neighbourhoods hence constructed leprosy simultaneously as an ambiguous category. On the one hand, it was a misfortune of the worst kind; on the other hand, it was perceived as an advantage to belong to the leprosy-affected community. The existence of the colony was simultaneously perceived as a problem and a solution to social and economic challenges. The aim of national agencies to re-integrate colony members into their families and communities is therefore far from being a straightforward resolution.

Last but not least, leprosy-affected people living outside the colony perceived the colony members as widely different from themselves, whilst stigma affected both groups. This finding further approves that the differentiation between colony members and others derived at least as much from community membership as from stigma.

It can therefore be concluded that approaching social dimensions of leprosy by focusing exclusively on the notion of stigma is based on a limited understanding of social relations between leprosy-affected people and others. I regard it insufficient to address social aspects of leprosy exclusively through the lens of stigma concepts that are unable to overcome the distinction between people discriminating against leprosy as the ‘stigmatisers’ and leprosy-affected people as the ‘stigmatised’. Such an understanding of stigma does not help to understand why leprosy-affected people from the adjacent neighbourhood disassociated themselves from the colony members, whilst both groups were equally afflicted with the disease and had developed the same kind of deformities. Programmes with the aim of reducing stigma rather need to approach stigma relations as embedded in various interrelated physio-emotional and socio-cultural processes. This paper further challenges the commonly held notion of leprosy-affected people as passive receivers of stigma, and rather emphasises the need to consider them as stakeholders who develop their own strategies to cope with the effects of stigma. The insights from this study will hopefully facilitate re-thinking current approaches to stigma reduction in leprosy.

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