

The Dynamics of Stigma in Leprosy¹

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ABSTRACT

Leprosy in Nepal is a stigmatizing disease. This paper explores the different coping strategies employed by people affected by leprosy to manage stigma. It is based on a qualitative study conducted in the eastern part of Nepal. It will show that a difference exists between experienced stigma and the anticipation of stigma. Both types of stigma result in different coping strategies. In managing stigma people go through different phases. This paper will show that stigma is a dynamic process, and I will elaborate on the concealment cycle, as developed by Hyland, to produce a more detailed understanding of the stigmatization process in Nepal. Doing so, it highlights the importance of a mutual concealment phase and the importance of triggers to exposure and discrimination. Changing from one phase to a subsequent phase in the stigmatization process is always triggered. It highlights further that even within the same culture and even the same village, social differentiation makes a significant difference on the impact of stigma and the coping strategies employed in managing stigma. Stigma enforces already existing inequalities in social class, gender, and age.

RÉSUMÉ

La lèpre au Népal est une maladie stigmatisée. Cet article étudie les stratégies variées utilisées par les personnes souffrant de lèpre pour éviter la stigmatisation. Il utilise des données d'une étude qualitative conduite dans la partie Est du Népal. Il montre que des différences existent entre une stigmatisation déjà vécue et une stigmatisation anticipée. Les deux types de stigmatisation résultent en des stratégies différentes d'évitement. Pour éviter la stigmatisation, les personnes passent par plusieurs phases. Cet article va démontrer que la stigmatisation est un processus dynamique, et je vais m'étendre plus particulièrement sur le cycle de dissimulation, comme développé par Hyland, afin de mieux comprendre et de façon plus détaillée le processus de stigmatisation au Népal. Ce faisant, cet article montre l'importance de la phase de dissimulation mutuelle et de l'importance des facteurs déclenchant lors de la révélation et de la discrimination. Le changement d'une phase à la suivante en stigmatisation est toujours déclenché. Cet article met de plus en lumière que, même au sein d'une même culture et dans le cercle d'un même village, la différenciation sociale introduit une différence significative sur l'impact de la stigmatisation et dans les stratégies d'évitement dirigées contre celle-ci. La stigmatisation met en application et fait valoir les inégalités déjà existantes de classe sociale, de genre et d'âge.

RESUMEN

La lepra en Nepal es una enfermedad estigmatizante. Este trabajo explora las diferentes estrategias seguidas por la gente afectada de lepra para sobreponerse al estigma. Se basa en un estudio cualitativo realizado en la parte oriental de Nepal. Muestra que existe una diferencia entre el estigma ya experimentado y la anticipación al estigma. Cada tipo de estigma se acompaña de diferentes estrategias de protección. Para manejar el estigma la gente pasa por diferentes etapas. El estudio muestra que el estigma es un proceso dinámico y en él se analiza el ciclo de confinamiento desarrollado por Hyland para entender de manera más detallada el proceso de estigmatización en Nepal. Al hacer esto, se resalta la importancia de una fase de confinamiento mutuo y la importancia de eventos que disparan la exposición y la discriminación. El cambio de una fase a la fase subsiguiente en el proceso de estigmatización es siempre un evento disparado. El estudio subraya además que dentro de la misma cultura y aún en la misma localidad, la segregación social influye de manera muy importante en el impacto del estigma y en las estrategias seguidas para manejarlo. El estigma refuerza las desigualdades ya existentes en clase social, género y edad.

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Stigma is a dynamic process. Many people with leprosy are affected by stigmatization. For the individual, stigma often leads to a "spoiled identity" (6). After a person is labelled as leprosy, there are negative social consequences for this person and his or her family. Stigma marks the possessor as socially unacceptable or as an inferior being, and the effect of "being labelled in this way is that people's stigma can come to dominate the perception that others have of them and how they treat them" (12). Van Brakel, in his review on measurement of stigma, concluded that "despite enormous, cultural diversity, many areas of life affected by stigma are remarkably similar in different countries. They include mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious functions" (14). However, how people are affected by stigma varies from culture to culture.

It is important to regard stigmatization as a process (9, 11, 16). During this process the label or attribute given to a person influences the social interaction between the labelled person and others. The person is labelled negatively, his or her status is devalued, and consequently the label could have negative consequences for this person, personally and socially. As Hayward and Bright (7), and Bainson and van de Borne (8) argue, the label modifies the actions of others towards the labelled person. Bainson and van de Borne further argue that probably the often present physical marks in leprosy generate a negative response in other people. According to Goffman (6), persons who share the same cause of stigma tend to have similar learning experiences in the management of the stigma, and they go through the same socialization process. He conceptualizes this as "the moral career of stigma." The moral career is the sequence of adjustments people make in managing stigma. Similarly, Alonzo and Reynolds (1) and Hyland (9) describe stigmatization as a dynamic process, in which the affected person passes through several phases. In each phase, the person affected copes by using specific coping strategies and in each phase, other people's responses are different.

The stigma trajectory as developed by Alonzo and Reynolds (1) shows how persons affected by stigma struggle with the

expected stigma and how they cope with it. Scambler (12) differentiates between felt and enacted stigma. Felt stigma refers to the fear of being stigmatized and enacted stigma is the actual discrimination. In the stigma trajectory, people move from a felt stigma towards being actually stigmatized. The dynamics of the stigma trajectory is the result of the constant interaction between the person affected and other people (1). In the stigma trajectory, changing from one phase to the subsequent phases depends very much on the development of the disease, and in this, the development of visible symptoms. Additionally, characteristics of the individuals affected and the contextual situation can influence this process and the impact of stigma. Some people may have better coping skills or "passing" skills than others, or in some situations the stigma attribute is more visible and powerful than in other situations. Stigma can on occasions be

"expansive," pervading all corners of an individual's biography and identity, and on other occasions "containable," limited and controllable in terms of consequences and, more importantly, personal and social identity (1).

Hyland (9) in her socio-cultural study of leprosy in Nepal also developed a kind of stigma trajectory in which the different coping styles of the stigmatized people are explained. She described this process as the "concealment cycle." The difference with the stigma trajectory can be seen immediately in its name. Hyland defines it as a cycle, as a recurrent process and not as a linear process. This is explained below. The concealment cycle is based on the assumption that persons affected will try to conceal their disease for as long as possible, and this is in order to keep their social integrity intact. Social integrity is defined as a person's place or position in the community. According to the concealment cycle people affected by leprosy will try to manage stigma by concealing the disease and if questions are asked about symptoms, or the person needs to go to the clinic, attention is distracted by telling "stories." This "story telling" is a kind of concealment in which the person is "saying something and not saying what (it is) wished to keep secret" (emphasis in original) (9). In the next step of

the concealment cycle, the person affected feels that his or her social integrity is threatened. This may happen when questioning or the curiosity of the community increases. To preserve his or her social integrity the person affected may cope by withdrawing. Withdrawal during this stage results in people stopping their treatment, leaving the village together with their families, or leaving alone in order to work in another community.

Hyland (9) then discusses how the stigma can be exposed at different levels: exposure can differ from private exposure to public exposure. Private exposure refers to the person affected knowing that others are talking about him or her. This talking about him or her can change from private curiosity, via suspicion and gossip to "public silence and private slander." Hyland draws this last term from Miller (10) and it refers to others knowing about it, but avoiding open conflict. Miller (10) argues that people in rural communities in Nepal try to avoid conflict, and in order to provide each other with some "temporal space," mutual concealment can be chosen. Miller found that it can then happen that in the homes of others, people talk about the disease of the affected person (private slander), but in public people still show politeness and respect (public silence). Others in the community often "wait and see" for the unfolding of events. The study presented in this article demonstrated that this stage of mutual concealment in a social interaction is very useful in understanding that actual stigmatization only occurs after the action (or response) is "triggered" (8). If, during this "wait and see" phase, nothing further happens or when others know the person takes treatment, the process can reverse itself and social integrity is regained (8,9). If however, the symptoms remain or become worse, or if the person discontinues his or her treatment, the disease can become publicly labelled and result in public discrimination. It is here that the differences between the (linear) process of the stigma trajectory and concealment cycle become clear. In the concealment cycle, a person can regain his or her social integrity, a person can move from a later phase to an earlier phase. In the stigma trajectory such reversal is not possible.

Hyland shows that in the last stage of the cycle, public reactions can differ; from ask-

ing the person affected to sleep and eat separately within the family, to living in a separate shelter in the village, or to being sent away. People who were asked to eat and sleep separately or to live separately in the village can regain their social integrity. Only the persons being sent away have no chance of regaining their social integrity. However, Hyland is not clear in *why* these reactions differ, the results of the study presented below (8) show that the social differentiation existing in Nepal affected the reactions of others towards people with leprosy. With these findings I elaborated the concealment cycle.

Alonzo and Reynolds (1), and Hyland (9) show that the stigmatization process is a dynamic process, which is continuously shaped and re-shaped, and very much depends on social interaction. Both recognize the importance of the progress of the disease on the impact the stigma has on social interaction. Both studies of Alonzo and Reynolds, and Hyland are very useful in understanding the stigmatization process that occurs and the different phases a person affected by leprosy goes through. The study of Hyland was conducted in western Nepal and the patients interviewed were people who were registered in a specialized leprosy hospital and who already had deformities of the hands and feet. This paper is an attempt to further develop the understanding of the stigmatization process drawing on a study based on interviews with people affected by leprosy who were registered at general health posts. The people interviewed had mostly less advanced leprosy than the people interviewed in the study of Hyland. I did not set out to study the stigmatization process *per se*; rather this paper reflects themes that emerged from a larger study of understanding people's adherence to leprosy treatment.

METHODS

The data presented here were drawn from a larger research project on adherence to leprosy treatment from the view of the persons affected by leprosy (8). To accomplish this 76 people were interviewed in depth about their life experiences with leprosy and its treatment. People who had their patient cards in the general governmental health posts situated in the project area of

the Eastern Leprosy Control project (ELCP) were included in this study. Two groups of people were interviewed: people who had completed their leprosy treatment and people who had discontinued their treatment. People were selected based on a random sampling technique. An interview guide was used consisting of 11 themes. People were interviewed in their homes. Interviews lasted for 1½ to 2 hr and were tape-recorded. The recordings were translated and transcribed and were analysed by using a grounded theory approach⁽¹³⁾ and the pattern matching methodology as described by Yin⁽¹⁷⁾.

In total, 29 people who discontinued treatment and 47 people who were released from treatment were interviewed. These people lived in different parts of the ELCP area. A good distribution existed between those who lived in rural and urban areas, and those belonging to the different tribes and religions in the area. More men than women were interviewed. More detail about the method and sample is available elsewhere⁽⁸⁾.

Some background information on Nepal. Nepalese society is complex in terms of caste and ethnic groups. There are the groups that are contained within the Hindu caste system, as well as other ethnic groups. Officially, Nepal is a Hindu Kingdom, but it includes Buddhist, Muslim, and Christian minorities. In 2004, the literacy rate was estimated to be 62.7% among the males and 27.6% among females⁽³⁾. In Nepal, strong hierarchies exist between individuals, families, and communities. As Nepal is a Hindu society, social relationships are influenced by religious or ritual norms and values, but also by economic and political hierarchies. In the past, the ritual hierarchy was the same as those defined by economic and political power. This has changed, however. A person of a high ritual status does not automatically possess a high economic and political status any longer. The three different types of hierarchy are, however, very much interrelated. It is not possible to talk about the status of a person, as a person's status depends on the many different roles and powers the person has in his or her family and in his or her community, and also on specific contexts and situations.

RESULTS

The results of the study illustrate the difference between expected stigma, and experienced stigma. The majority of the people interviewed expected that once others knew about their disease, they would be separated. These expectations resulted in people employing various coping strategies to prevent stigma. However, people whose disease was exposed tried to make their disease less obtrusive by employing other coping strategies. First, I will discuss the strategies employed in managing expected stigma, the so-called strategies of concealment. Subsequently, the coping mechanisms in response to experienced stigma are discussed. These strategies are summarized in Figure 1, which is my development of Hyland's concealment cycle. Within these discussions the importance of triggers to exposure and discrimination, and the influence of social differentiation on the impact of stigma is shown.

Strategies of concealment caused by expected stigma. When asked about their fear and actual actions taken towards them, most of the respondents produced a narrative about other persons who had leprosy and who were treated badly by their communities. These narratives showed something of the expectations the interviewees had of how family and community members would treat them. These narratives were about people being stigmatized and had been told to interviewees by family or community members, or were based on observations they had made themselves. A man who had many patches became very worried after the health worker diagnosed his disease as *Kustha Rog* (Nepali word for leprosy). He remembers images of persons affected by leprosy who were begging in the streets of Calcutta. He said:

I had seen beggars with *Kustha Rog* when I was in Calcutta. When I got *Kustha Rog* myself I used to feel scared thinking about those other people who had *Kustha Rog*. . . In our village there is a saying that if one of the villagers gets this disease and if another person is close with the infected person, or sits with, eats the *jutho* (a person's food leftovers) of, or if the husband, or the wife has the disease, then the other person will be in-

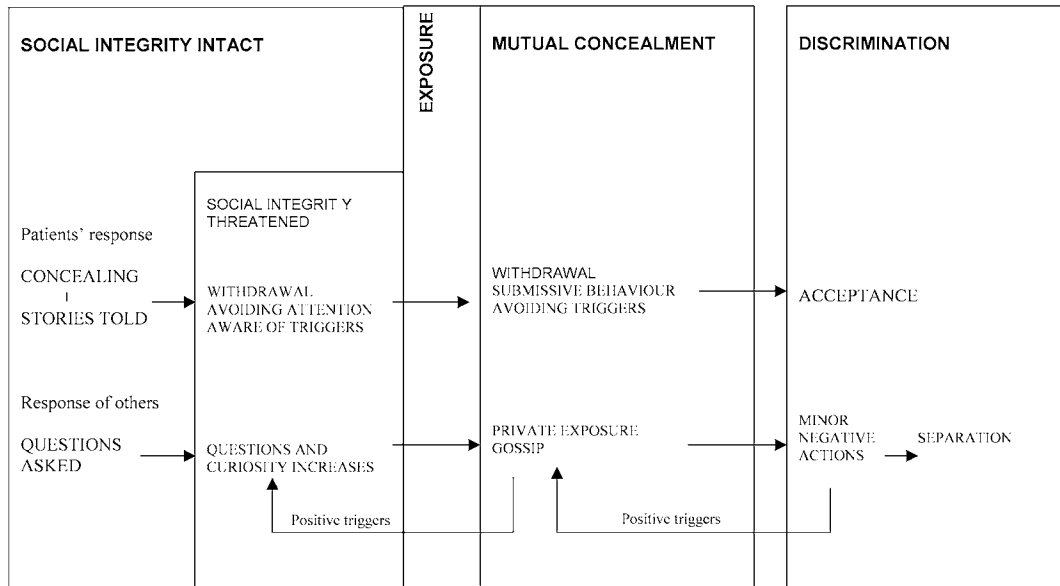


FIG. 1. The stigmatization process.

fectured with the disease. . . In my village the people do not tell me not to walk with them, sit or eat with them, they did not say or do anything. My disease is not clear and that is why most of them could not find out.

The narratives told about other people affected by leprosy however, were always about people who had wounds and deformities and many expected that the development of wounds and deformities would consequently result in being discriminated.

Another important finding related to expectations was that the majority of the people interviewed, including those without wounds, expected that others, after hearing which disease they had, would immediately act negatively towards them. The diagnosis of leprosy was seen as a trigger to discrimination.

Because of these expectations, felt stigma led to a strategy of concealment, which had the effect of reducing the incidence of enacted stigma and retaining one's social integrity. Almost all interviewees opted for concealment from other community members; 43 (out of the 76) interviewees were able to conceal their disease from their communities. Thirteen people had also concealed their disease from their family members.

In trying to conceal their disease, people employed several strategies to avoid attention. These strategies were triggered by events happening to them. When others asked them questions about symptoms or side-effects they had noticed, or about the interviewed person going to the clinic regularly, many interviewees mentioned that they told "stories." Stories told were that they had ringworm, had a simple skin disease, had become black because of the sun, had a wound because of the type of work, or needed treatment because of another disease. The function of these "stories" was to distract attention.

If the symptoms of leprosy developed or increased, the questioning and curiosity of other people about their symptoms increased, and the respondents perceived that their social integrity was threatened. In this stage they tried to manage the stigma by avoiding situations in which enacted stigma could be triggered, or to diminish the number of triggers. Some people, when they had visible signs of leprosy, withdrew temporarily until their symptoms had improved. One woman, who was a widow, developed some white patches on her hands and face. After people questioned her about it, she took her children with her

and went to a family member in a large city nearby. There, she started treatment and remained in the city until the patches were less visible. Another man, who developed a patch on his face which became swollen and festered at the beginning of his disease, reported how he tried to stay inside the house or around the house until the swelling went. Some went early to their fields to avoid meeting other community members.

The concealment strategies employed were very much linked to the hierarchical position of the individual within their community and their family. To some the impact the stigma had on their lives was less than on others. Family and community status influenced the reaction of others towards them.

The majority of the people with a higher status succeeded in concealing their disease from other community members. Normally, when a person developed many patches, questions were asked, however people with a higher status believed they were protected against questions being asked. (Note: Interviewees mentioned several factors to differentiate themselves from others and which they believed showed their status within the family and community. I used these factors to determine a person's status within the family and community. These factors and their consequent classification are given in the appendix.) Questions were asked of some people with a higher status, but they could avoid the questions by telling a "story." A few people stated that they believed that others were gossiping about them. Half of the people with a lower community status were able to conceal their disease, but questions were asked of relatively more people with a lower community status. Their status in the community did not protect them from these types of questions. Some mentioned that they had to accept the behaviour of others. They said things like:

How could I discuss it with them. Of course, they scold me. Whose mouth can I keep shut? . . . Then we understand ourselves and keep quiet.

Another example gives the comments of the wife of a person affected by leprosy on the negative behavior of villagers:

Politicians should make some arrangements for the poor people, but they do not care about us. There would be no difference between rich and poor people if they took a little care of the poor people. We are poor people and that is why other people come here and beat my husband but the villagers do not come and stop them.

Miller (10) in his discussion on decision-making in villages in Nepal, argued that it is not so important what people think about each other, but what people *say* about each other; it is words that give weight to attitudes. Although people with a higher status who had visible signs of leprosy may still fear the exposure of their disease, their status in the community protected them from others asking questions, and thus from actions being taken.

The results of the analysis showed that within the family different hierarchies could be identified, based on decision-making power, gender, and age and within these between the people who could contribute to the family income and those who could not (see appendix). Men with decision-making power who could contribute to the family income all concealed their disease from other family members. Some had made their decision not to inform other family members as an attempt to avoid causing family concern. One man said about this:

I did not tell my family about the disease. I was afraid they would be tense and get worried. We do not have enough food to eat and clothes to wear. I thought that whatever happens, will happen to me only.

These people could conceal their disease because, due to their position, other family members could not question them about their disease. As one man said, "I am the guardian of the house and I can decide what to do." Such an attitude makes it difficult for others to inquire about a disease which they might believe to be dangerous. People who did not belong to this group of decision makers were very much aware of their position within the family and they expressed it as vital that they contributed to the family income. These people lived dependent lives, and were greatly influenced

by other family members, and thus contributing to the family income provided them with a certain status or secured their position within the family. The felt stigma among them was very high.

Strategies employed in managing experienced stigma. During the interviews, it was not easy for the interviewees to discuss the actual stigmatizing behavior of family and community members towards their disease. Many tried to avoid the subject and many cried when they described the behavior experienced. Thirty people mentioned that their disease was known to their communities, of whom 20 experienced negative behavior from other community members. Six people mentioned that their community members were “waiting to see” what would happen, and only four did not experience any negative behavior from others. In cases where the other family members knew of their disease, negative family behavior was less common. This happened to 10 of the 60 people. The majority of the interviewees received family support.

After their disease was exposed to other people the respondents were not immediately publicly discriminated against. In this phase, people whose disease was exposed to other community members adopted a strategy of “covering;” they took all possible steps to reduce the salience of their stigma for others. They were living in constant fear that they would be sent away from their families and be expelled from the village. Some people withdrew from social life, by going to their fields in the early morning, by working outside the village, or by staying near the house. Two people started working as migrant laborers in India and only came back after their symptoms had diminished. Others stayed in the village, but avoided confrontation by sitting apart, not sharing utensils, not visiting public gatherings, etc. Some people tried to stay at home and work near the house. They tried to live and work unnoticed and had developed a submissive attitude.

As I argued above, in rural communities in Nepal people try to avoid conflict and provide each other with some temporal space. As this period of mutual concealment could last for a long time I elaborated the concealment cycle with a separated phase, the phase of mutual concealment. In

this phase, people may gossip behind their backs and talk about the disease of the affected person (private exposure), but in public people still show politeness and respect. People “wait and see” what will happen.

The results of the analysis show that actual public discrimination only occurred in response to one or more triggers. Several negative triggers existed that led to exposure of the disease and people tried to diminish the effects of these triggers and situations in which these triggers would be obtrusive. Negative triggers that resulted in public exposure were increase in visible symptoms, development of wet wounds, the regular visits to the clinic, specific side effects, like reddish-brown discoloration of the skin, swelling and weakness, and inability to contribute to the family income. A relationship was found between status and the type of negative actions taken. For people with a higher community status, only persistent and severe wounds were triggers to other community members acting negatively towards them. For this reason, some people with a higher status were no longer visited by other community members. However, these negative actions could be temporary and were situation specific. In this group of people with a higher status, no one was threatened with expulsion from the village. There were more negative actions directed against people with a lower status and after they had developed a severe and persistent wound, they experienced more severe negative actions. Some people were even threatened with expulsion or had been already expelled. The majority of the people whose disease was exposed and who experienced negative behavior from others, believed they were not in a position to do anything about it and had to accept what was happening, or as one interviewee said:

The villagers, my neighbors know about my disease. Sometimes when I get into an argument people say bad things to me, like “you have *Soon Bairi*” (leprosy). At that moment I feel really bad, and keep quiet thinking ‘what to do if I do have that disease.

Of the people whose disease had been exposed to their families, this knowledge was in some cases only shared by their closest

family members (wife, husband, or parents), while in other cases it was only known to the nuclear but not the extended family. Some had informed their family members themselves of the diagnosis of leprosy, while others had delayed this and it had been exposed later, after other family members had found the medicines, questioned the regular visits to the health post, or the interviewee had made an admission after a long period of being questioned about it. Due to the fact that leprosy was viewed as being very contagious, many interviewees had adapted their behavior, or had been asked to change it to avoid infecting other family members. Most of them did not give their *jutho* to other family members and stored their food utensils separately, and in some cases even their bedding and clothes. Some interviewees withdrew themselves from certain aspects of family life; they started to sit, eat, and sleep separately, but continued to join the family in other activities. A few were no longer touched by others, or were asked to live separately on the family compound, outside the family houses. For most, this separation was only temporary. After the symptoms had diminished or the wounds had healed, the person would be allowed to move back into the house. One man developed a wound, and only after the advice of other people did he go to the health post. Here they diagnosed his disease as *Kustha Rog*. He informed his family about the diagnosis and was then asked to eat and sleep separately until his wounds healed and he moved back into the house. He said:

No one in my family ate with me for at least two to three months, because they thought this disease was contagious. All of them felt bad and advised me to take my medicines continuously. They said that taking the medicines could cure my disease.

The different family hierarchies had an impact of the effects of stigma and coping strategies employed. Decision-makers withdrew themselves from family life to avoid transmission and of fear of the social consequences. The position of non-decision-makers within the family did not change much as long as they showed submissive behavior and contributed to the family in-

come and as long as they did not develop severe wounds, weakness, or illness. Some differences were found in comparing women with men who were not decision-makers. Visible signs of leprosy did not result in negative actions against men who were not decision-makers. However, visible signs of leprosy were triggers for negative actions towards some women. The women who had not experienced negative family behavior belonged to better-educated families, or where knowledge about leprosy and its treatment existed. Further, age was also an influencing factor; in the group of people above 50 yrs, it was found that to these people it was important to contribute to the family income. They helped their families by doing minor work. After developing wounds and deformities with which they could not work anymore, four people were sent out of their villages. Interviewees who were less than 15 yrs old had all received a great deal of family support. These children were kept at home.

DISCUSSION

The stigmatization process as a interactive and dynamic process. The results of the analysis demonstrate that a stereotypical view about leprosy is still dominant. Although the majority of the interviewees expected to be separated, few people were actually expelled from the village or separated within the community or family. In the past when no treatment existed for leprosy, people were sent out of the villages due to fear of transmission, and thus the stereotypical thinking is mostly based on this past reality. This study shows that people employ a variety of coping strategies to manage the stigma attached to leprosy. As the stigmatization process is based on the interaction between people, the strategies employed by individuals depend very much on the expected and experienced (re)actions of others towards them. The different phases of this stigmatization process are demonstrated in Figure 1, and described above. This stigmatization process is an elaboration of the concealment cycle as developed by Hyland (9). The original concealment cycle is extended with the phase of mutual concealment. After the disease is exposed to others this does not immediately result in public discrimination. A kind of "wait and

see" attitude existed, waiting for things to happen. Another important finding of this study was that the stigma caused by leprosy does not have to be permanent. The original cycle is further extended with influencing triggers.

The importance of triggers. The results of the analysis showed that going to a subsequent phase in this stigmatization process is always triggered. The type of triggers had an impact on the coping strategies and also on the type of stigmatizing actions of others. Not only visible symptoms of the disease were perceived as triggers to exposure and discrimination, also other events related to the disease and its treatment were perceived as triggers. Other triggers to exposure and discrimination included regular visits to the clinic, the blisterpack of the medicines, and the side-effects of the Multi-drug Therapy treatment (esp. weakness, and a darkening of skin due to the clofazimine). Next to these so-called negative triggers, some positive triggers were also reported. The knowledge that the interviewees were on treatment resulted in others being willing to wait and see what would happen. Likewise, improvements observed in the symptoms also contributed to a "wait and see" behavior pattern. Thus, depending on the type of trigger, a positive or a negative trigger, stigmatization can become more severe or diminish. In the elaborated cycle a person can move to a subsequent phase into the model or can move back to a previous phase.

The importance of social differentiation in stigma. Managing stigma has to be regarded in a wider context. The impact of stigma is related to individuals' position in the family and community hierarchies. Social interaction between people is based on social rules and norms that are related to their position within the hierarchies. As stigmatization is a dynamic process and is based on interactions between people. The impact stigma has on a person's life reflects the general way people interact in the wider society. Because of their authority within the community, high status people could not be asked "curious," personal questions. Even after they had developed a stigmatizing disease, other people could still not ask them questions, and negative behavior was only shown if the disease reached an advanced

stage. Lower status people were already vulnerable to scolding in their everyday life and were never permitted to attract attention. Where, in other circumstances, any mistake or failure would be noticed and questioned, here the disease leprosy was the trigger for negative actions. Leprosy legitimized negative actions. This study demonstrates that the stigma in Nepal could not only *exist*, as Waxler⁽¹⁵⁾ stated, because of the hierarchical nature of Hindu society, but that the hierarchical society also *explains* the differences in the impact of stigma between people holding different positions within the hierarchies, or as concluded by Parker and Aggleton⁽¹¹⁾ stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality.

CONCLUSION

What are the implications of these findings for interventions aimed at reducing the stigma of leprosy? As leprosy is still related to images of people with deformed hands and/or feet and who are sent away. It is not surprising that the majority of the patients, when asked about strategies for stigma coping, recommend to keep the diagnosis leprosy a secret or even to avoid contact with other people. Communities need to be targeted with information regarding leprosy and stigma, efforts should be made to change negative attitudes and practices. Particularly the linkage with the stereotypes dangerousness and infectiousness^(5,8) provokes adverse reaction among the public. Therefore, messages like "leprosy is not infectious anymore after starting treatment" should be one of the key targets for anti-stigma interventions. Research done within the mental health field showed that strategies aiming at education and contact had impact on the attitudes about mental illness⁽⁴⁾. Members of the general public who interacted with a person with mental illness exhibited large changes in stigmatizing attitudes. Further, interventions are needed on the individual level, aiming at empowering the affected individual. This could include counselling, learning coping skills and self management, meeting places, practical assistance, and peer support.

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REFERENCES

- ALONZO, A., and REYNOLDS, N. Stigma, HIV and AIDS: an exploration of a stigma strategy. *Soc. Sci. Med.* **41** (1995) 303–315.
- BAINSON, K. A., and BORNE, B. V. D. Dimensions and process of stigmatization in leprosy. *Lepr. Rev.* **69(4)** (1998) 341–350.
- C.I.A. (2004). *The World Factbook*. Washington. <http://www.cia.gov>
- CORRIGAN, P. W., EDWARDS, A. B., and GREEN, A. Prejudice, social distance, and familiarity with mental illness. *Schizophr. Bull.* **27(2)** (2001) 219–225.
- DE STIGTER, D. H., DE GEUS, L., and HEYNDERS, M. L. Leprosy between acceptance and segregation. Community behavior towards people affected by leprosy in eastern Nepal. *Lepr. Rev.* **71(4)** (2000) 492–498.
- GOFFMAN, E. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, Inc., 1963.
- HAYWARD, P., and BRIGHT, J. A. Stigma and mental illness: a review and critique. *J. Mental Health* **6(4)** (1997) 345–354.
- HEYNDERS, M. L. *Understanding Adherence in Leprosy: Experiencing and Making Sense of Leprosy and Its Treatment in Its Social Context. A Qualitative Study Conducted in the Eastern Terai Region of Nepal*. Faculty of Health, South Bank University, London. Ph.D. thesis, 2002.
- HYLAND, J. E. *Socio-cultural Study of Leprosy in Nepal; Compliance, Patient Illness Care Patterns and Health Education*. School of Education, Department of Community Health, University of Tasmania, Tasmania. Ph.D. thesis, 1993.
- MILLER, C. J. *Decision Making in Village Nepal*. Kathmandu, Nepal: Sahayogi Press, 1990.
- PARKER, R., and AGGLETON, P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc. Sci. Med.* **57** (2003) 13–24.
- SCAMBLER, G. (ED.). *Sociology As Applied to Medicine*, 4th edn. London: W.B. Saunders Company Ltd., 1997.
- STRAUSS, A., and CORBIN, J. Grounded theory methodology. An overview. In: *Strategies of Qualitative Inquiry*. London: Sage Publications, 1998.
- VAN BRAKEL, W. H. Measuring leprosy stigma—a preliminary review of the leprosy literature. *Int. J. Lepr. Other Mycobact. Dis.* **71(3)** (2003) 190–197.
- WAXLER, N. E. Learning to be a leper: a case study in the social construction of illness. In: *Social Contexts of Health, Illness, and Patient Care*. Cambridge: Cambridge University Press, 1981. pp. 169–191.
- WEISS, M.G., and RAMAKRISHNA, J. Stigma interventions and research for international health. 3-12-2001. <http://www.stigmaconference.nih.gov/finalWeisspaper.htm>.
- YIN, R. K. *Case Study Research. Design and Methods*. 2nd edn. London: Sage Publications, 1994.

Appendix. Different factors determining a person's status.

- **Land ownership** and size of the land. This was about what the person affected described concerning income received from the land, and whether its produce was sufficient to live on for a whole year, without the need for supplementary paid work.
- **Occupation.** Type of occupation of all family members. I used the categories developed by Rao (1992)*. He defined nine categories for occupation: landless

labor, share cropper, land owner, employ others on land, non-agricultural service, artisan, owner of an industry, other occupations, and unemployed.

- **The educational level** of the patient or other family members. For some affected persons interviewed, it was very important to mention that they could read. The ability to read gave them a certain status or position within the community.
- **Type of family.** Being a nuclear or joint family, and type of family structure. Some joint families were those that had lived in the community for many generations. This and the presence of several married brothers gave the family a higher status.

* Rao, K.V. (1992). *Leprosy in Rural India*. Delhi, Manak Publications PVT LTD.

- **The type of housing** the family had. It made a difference if the family lived in a wooden, two-story house or in a hut made of mud or straw.
 - **Political status.** Some people stated that they were active members of a political party. Being an active member of a political party means that people can influence some decisions regarding the whole village, such as planning of roads, taxes, etc.
 - **Ritual status.** Some people were traditional healers, or were Brahmin priests, which gave them a higher status.
- Different cross-cutting factors acted together to give rise to a person's status. If for example, a person was a landowner, I categorized this person as being of higher status. If a person lived in a mud hut, was a day laborer and mentioned that he or she had days without income and thus food, I categorized this person as having a lower status. Active members of a political party, or people with a ritual status, or shopkeepers, were mostly categorized as higher status, though not all factors were congruent. The different categories as used in this study are shown below.

Status in the community.

Higher community status

Protected against questions being asked.

Majority succeeded in concealing their disease from other community members.

Only persistent and severe wounds were negative triggers resulting in negative behavior of others towards them.

No expulsion reported.

Lower community status

Had to accept the behavior of others.

Only half of them were able to conceal their disease from other community members.

Experienced community pressure.

Negative actions reported, including expulsion.

Status in the family.

Decision-making power

Hold a more independent position in the family.

On occasions, they withdrew from family life to avoid transmission and some concealed their disease out of fear of the social consequences.

Negative triggers were having severe (wet) wounds and some toes missing.

No decision-making power

Dependent of other family members.

Their situation did not change much so long as they showed submissive behavior and contributed to the family income and did not develop a severe wound, weakness, or illness.

Minor symptoms could lead to negative family behavior.

Men

Men constituted the majority of those with decision-making power.

Men with decision-making power concealed out of concern for the other family members, the other men out of fear of exposure.

Women

Women tried to conceal their disease and showed a submissive attitude.

Had to accept the behavior of others, and were very vulnerable to negative actions.

Old age

On occasions the oldest person in the family was not respected and sometimes even regarded as a burden. The ability to contribute to the family income was important.

Child

Out of concern about their children's future all children affected by leprosy received family support.