

Experiencing leprosy: perceiving and coping with leprosy and its treatment. A qualitative study conducted in Nepal

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Summary The way people interpret their disease and its treatment, or the meanings of these, has an impact on the way they deal with their disease and its treatment; meanings shape actions. In this article, the influence of the patients' interpretations on their coping with leprosy and its treatment, their help seeking and adherence behaviour is explored. This article describes the findings of a qualitative study, in which 29 people who discontinued treatment and 47 people who were released from treatment were interviewed in depth. All were registered at general health posts. Exploring the meanings of leprosy and its treatment in patients in Nepal resulted in the identification of six different categories of meanings. Each of these influenced the way people coped with leprosy and its treatment, their help seeking and adherence behaviour. These different categories are discussed. The main conclusion is that the explanatory models of the interviewees and of the health worker are different and that if we want to improve our leprosy services more health education has to be given whilst at the same time listening more carefully to those affected by this disease. This will give us greater insight into the way people understand their disease and its treatment and the measures we can take to prevent discontinuation of treatment.

Introduction

WHY MEANING IS IMPORTANT

The understanding of health and illness can vary across different contexts, environments, and cultures. MacLachlan¹ shows that symptoms of a disease can be interpreted differently. What in one culture can be interpreted as illness does not have to be so in another culture, and a given disease can have different symptoms in different cultures. He argues that symptoms of a disease can be 'culture bound'. Helman² argues that 'both the meaning given to their symptoms, and their emotional response to them, are influenced by their own background and personality, as well as the cultural, social and economic context in which they appear. In other words, two individuals from different cultures or social backgrounds and in different contexts may interpret the same 'disease' (such as tuberculosis) or symptom (such as pain) completely differently. Moreover, this will affect their subsequent behaviour and the sorts of treatment they will seek out'.

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Waxler³ compared the social impact of leprosy in India, Tanzania, Ethiopia, and Nigeria. She found that the social definition, the social meaning of leprosy, differed from society to society. Waxler concluded that although the (biological) disease with its symptoms was everywhere the same, the (social) meaning of leprosy was very different and resulted in different (re)actions from community members. From the beliefs and expectations present in a specific culture the persons affected by leprosy 'learn to be a leper', learn how to respond.

As perceptions of what constitutes illness, the meaning of a specific illness, and how illness is experienced, vary between cultures, the concept of explanatory models is very useful in exploring the meaning and experience of leprosy for the persons affected by it. The term 'explanatory models' was introduced by Kleinman⁴ and he defines it as follows 'explanatory models are the notions about an episode of sickness and its treatment that are employed by all engaged in the clinical process' (p. 105). Kleinman's explanatory models are an attempt to understand health, illness, and healing in society as a cultural system. All people when they are ill, have their own idea about their suffering; they all develop 'explanatory models' to understand this suffering. Explanatory models are sets of beliefs or understandings that specify for an illness episode its cause, time and mode of onset of symptoms, pathophysiology, course of sickness, and treatment. Explanatory models are based on the general beliefs existing in a specific culture, but differ as to how they are formed and employed to cope with a specific health problem. Thus, the meaning of a disease and its treatment will affect people's coping strategies in dealing with their disease and its treatment, and consequently their help-seeking and adherence behaviour.

This paper reflects themes that emerged from a larger study of understanding people's adherence to leprosy treatment.⁵ This article presents only a part of the results of the larger study and concentrates on the way people interpret their disease and its treatment and the consequences of this for people's coping, help-seeking and adherence behaviour.

Methods and sample

To allow the interviewees to express their own perspectives on and their meanings and understandings of their disease and its treatment an open qualitative approach was used. Seventy-six people were interviewed in depth about their life experiences with leprosy and its treatment. Included in the study were: people who had their patient cards in the general government health posts situated in the project area of the Eastern Leprosy Control Project (ELCP), people who had completed their leprosy treatment ($n = 47$), people who had discontinued their treatment ($n = 29$), patients were registered as having (had) MB leprosy and people who had started their treatment no longer than 4 years before the interviewing (the research was conducted between 1998 and 2002). People were selected based on a random sampling technique. Approval had been received from the National Research Council of Nepal. An interview guide was used consisting of 11 themes. Based on a literature review, on 2-year working and living experience in leprosy in Nepal and after long discussions with leprosy staff and other social scientists, this interview guide was developed. This interview guide and the actual interviewing were pre tested. People were interviewed in their homes, after verbal informed consent was obtained. All people approached for interviewing did agree to be interviewed; some, however, requested to be interviewed further from home. Interviews lasted for 1.5–2 h and were tape-recorded. The recordings were translated and transcribed and were analysed by using a grounded theory approach,⁶ cognitive mapping technique, and the pattern

matching methodology as described by Yin.⁷ The coding of the first interviews and the use of the cognitive mapping technique were carried out in conjunction with other experienced qualitative researchers, these interviews were line-by-line coded. By using the cognitive mapping technique the first diagrams were developed and discussed within the research team. New patterns emerging were critically tested as to the meaning these had for the interviewee and compared with other interviews. The interviewed 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.⁵

In qualitative research, the aim is to try to develop a framework of understanding of explanatory factors or dynamics of social processes based on a synthesis of information emerging from a variety of data sources. In the current report, the aim is to develop an understanding of how people affected by leprosy experience their disease and its treatment. In this process, it is not the data of individual subjects or statistical inference from the study sample that is the most important, but the whole picture these data form together. To show commonalities and deviant cases and to differentiate between different groups I have used the words 'few' to indicate when only a few subjects shared a particular opinion (< 10), 'some' when around half of them shared a particular opinion and 'many' when a majority opinion is described (> 2/3).

Results

DIFFERENT CATEGORIES OF MEANING

Exploring the way people interpreted leprosy and its treatment resulted in the identification of different categories of meanings. These each influence the way people cope with leprosy and its treatment, their help-seeking and adherence behaviour. This is discussed below.

LATE HELP-SEEKING AS THE SYMPTOMS OF LEPROSY WERE NOT RECOGNIZED AS A DISEASE, OR NOT REGARDED AS LEPROSY

One of the categories of meaning that became apparent during the analysis was the way people interpreted their symptoms of leprosy and the influence these interpretations had on their help-seeking behaviour. Before the diagnosis of leprosy was communicated to them, many interviewees did not recognize their symptoms as being leprosy. To them, leprosy was associated with a disease in which people have wounds and deformities and thus they could only recognize leprosy through deformities and wounds.

Half of the people interviewed did not regard their symptoms as severe and thought that the symptoms would disappear by themselves and did not seek treatment. Symptoms they did not regard as severe were patches, minor swelling, *jhum jhum* feeling (tingling sensation), wounds caused by the heat of fire, and wounds that did not cause much trouble, or which did not increase in size and were dry. Most did not recognize these symptoms as a sign of a disease and thought they would disappear naturally. Others thought it was another, more common disease, like ringworm and rheumatism. For the patches and skin problems, a few went first to a traditional healer to get oil that they could apply to the skin. Only a few people took their own initiative to seek treatment from a medical practitioner. The majority, however, were advised by others to seek treatment at a health post or hospital and after this

advice most went to a private practitioner, health post or hospital. Others had told them that their symptoms could be *Charma Rog* (*skin disease*), or that their disease could be a serious, dangerous or major disease in which the ‘hands and feet will fall off’.

The other half of the interviewees had symptoms that they perceived as being severe, or after their symptoms began increasing, became worried. These included: an increase in the size and number of patches; swelling of the face and body; painful hands; wounds changing in size or becoming festered; wounds on feet; pain in nerves; fever; *jhum jhum* (pins and needles) feeling all over the body; and *kan kan* feeling (throbbing pain, mostly in nerves). Due to the fact that they worried about their symptoms, they visited a medical practitioner, but not because they suspected leprosy. Some were warned by others to seek treatment at a health post. In a few cases, where others suspected leprosy, they were advised to go to the health post immediately.

NAMES USED FOR LEPROSY SHOW A RELATIONSHIP WITH STIGMA COPING STRATEGIES AND ADHERENCE BEHAVIOUR

People did not only interpret their symptoms differently, but after they were informed about the diagnosis of leprosy, many different names were used to refer to the English word leprosy, in spite of the official Nepali translation of leprosy in *Kustha Rog*. These different words expressed the different meanings leprosy had for people affected. These can be divided into two groups. The first group refers to a type of leprosy in which the symptoms are mainly minor (numb skin, patches). The other type of leprosy is recognized mostly as a severe type of leprosy in which people have wounds and deformities. The different names for leprosy that were given are illustrated in Table 1.

The two groups of names refer to two different types of explanatory patient models. After the health worker had informed them they had leprosy or more specifically that they had *Kustha Rog*, not everyone agreed with this diagnosis. After the diagnosis was confirmed, 15 defaulters and 41 RFTs accepted or acknowledged they had *Kustha Rog*. As the explanatory models of *Kustha Rog* are similar to the explanatory models of *Kodiya*, *Kor*, big or dangerous disease, and *Bhagwan Rog*, I define all these explanatory models as the explanatory models of *Kustha Rog*. People perceived *Kustha Rog* as a progressive and stigmatizing disease, progressive in the sense that they expected because of their disease to develop wounds and

Table 1. The different names for leprosy

		<i>Literal meaning</i>
The minor type of leprosy:	Charma Rog	disease of the skin
	Soon Bairi	numbness
	Skin disease	
	Jhut	numbness
	Challa ko Rog	disease of the skin
The severe type of leprosy:	Chattak	disease of the skin
	Kustha Rog	disease of rotting flesh
	Kusthi	Kustha Rog
	Kodiya (Rog)	dialect for Kustha Rog
	Big or dangerous disease	
	Kor	leper
	Bhagwan Rog	disease from God

deformities. In this group of people who acknowledged they had *Kustha Rog*, people who had minor symptoms of leprosy reacted differently to the diagnosis than people who had more advanced leprosy. The people without wounds or deformities (five defaulters and 20 RFTs) explained that their disease was in its first stage and they expressed their fear that if their disease were to progress they would develop wounds and deformities, and consequently would be sent out of their villages. They mentioned that with early treatment, the advanced stage of the disease could be prevented. People who had wounds and deformities (10 defaulters and 21 RFTs) agreed with the diagnosis made by the health worker. As they already had wounds and deformities, the diagnosis corresponded with their own understanding of leprosy; and they wanted their wounds to be healed. The majority of the people interviewed expressed a strong motivation for completing their treatment. They feared they would develop wounds, or if they already had wounds, they wanted them to be healed. They knew that if the disease were not treated it would progress and this would have social consequences; they would be neglected, treated badly, and maybe even separated or expelled from the community. Due to this fear, they expressed their belief that they had to continue their treatment.

The explanatory models of *Charma Rog*, *Soon Bairi*, skin disease, *Jhut* and *Challa ko Rog* display similarities, but also differences from the explanatory models of *Kustha Rog*. In this group, people could deny having *Kustha Rog*. I define the results of the explanatory models based on the minor type of leprosy, as the explanatory models of *Charma Rog*. In these, I also include the people, who during the interviews did not supply a name for their disease. They referred to their disease as their 'problem', their 'symptoms', or their 'disease'. In total, 14 defaulters and six RFTs were included in the explanatory model of *Charma Rog*. After the health worker had informed them they had leprosy or more specifically that they had *Kustha Rog*, the reactions described by the people who believed they had *Charma Rog* differed from those of the people who acknowledged that they had *Kustha Rog*. From the former group of people who stated that they had *Charma Rog*, the majority of them denied having *Kustha Rog*. For them, the symptoms of *Kustha Rog* were wounds and deformities, in which case, in their interpretation, they could not have the disease as diagnosed by the health worker. Scambler⁸ argues that people's reaction to deny or reject the diagnosis of their stigmatising diseases could be because they regard their disease as an acute social liability. My findings are consistent with this, as some people denied or at least tried to 'negotiate' for a less virulent alternative diagnosis. They denied having *Kustha Rog* out of fear of stigmatization. Although people did not acknowledge the diagnosis of *Kustha Rog*, some people in this group were motivated to continue their medication. A few explained that *Charma Rog* and *Kustha Rog* were two different diseases, the treatment being the same for both.

Use of the name Charma Rog

People use the name *Charma Rog* in different ways and, as argued above, some of these interpretations of *Charma Rog* show associations with non-adherence to treatment. In a reaction to stigma, some people with minor symptoms of *Kustha Rog* mentioned that their disease was in its first stage and told 'stories' when questions were asked (more details on the coping strategies of 'telling stories' are discussed elsewhere,⁵ and is also discussed in 'The dynamics of stigma in leprosy' by M. L. Heijnders, *International Journal of Leprosy*, in press). One of these 'stories' was that they explained they only had *Charma Rog*. This was regarded as a minor skin disease, in which people did not have wounds and deformities.

Here, *Charma Rog* was believed to be a non-stigmatizing disease. On the contrary, in the explanatory model of *Charma Rog* people did not only use the *Charma Rog* out of defence, but they appeared to actually believe they had *Charma Rog*. This difference in the use of the word *Charma Rog* can be explained in several ways. Some people, as a way of managing the stigma, told the 'story' that they had *Charma Rog*. It could have been that some were very consistent in doing this and stated that they had *Charma Rog* during the interviews. Perhaps others might have begun believing it themselves. Their concealment behaviour would, in the case of *Kustha Rog*, be the normal reaction to the stigmatizing disease, and in the case of *Charma Rog*, a reaction to what they 'had learned to do', concealing the disease became a way of living with it. Another explanation for the use of the word *Charma Rog* can be found when comparing the number of the defaulters and the RFTs between the two types of explanatory models. It was found that half of the defaulters interviewed stated they had *Charma Rog*. This was in contrast with the RFTs of whom only ten people stated that they had *Charma Rog*. An explanation for this could be that the people who had discontinued their treatment and whose disease had not been cured yet, feared that it might continue to progress and that the stigmatizing reactions of others could still start and for those reasons denied having *Kustha Rog*. Denying *Kustha Rog* is thus related to feelings of insecurity and can thus be a strong contributing factor in non-adherence to treatment. Finally, an explanation for this difference in the use of the word *Charma Rog* could be that they really believed they did not suffer from *Kustha Rog*, as their symptoms were different.

The different uses of the word *Charma Rog* may thus refer to differences in interpretation of the disease leprosy, which have consequences for how people cope with their disease and its treatment.

PEOPLE ATTRIBUTED MULTIPLE CAUSES TO THEIR DISEASE AND SOUGHT HELP CONSEQUENTLY

As leprosy and specifically *Kustha Rog* was not just a disease, but was perceived as a progressive, stigmatizing disease, many people, after they were told that they had leprosy, questioned themselves as to how and why they had contracted it. The perceived causes of leprosy formed another category of meaning. Most of the persons interviewed attributed multiple causes to their disease. The different causes mentioned by the interviewees show great similarity with the categories found by Hyland.⁹

Some informants believed in a metaphysical cause. People believed their illness was God's will and their fate. They believed they had committed a sin in their previous life and that this disease was their punishment. Another cause, closely related to the divine punishment, is the belief that this sin and therefore this disease are inherited by future generations. A few informants believed that the disease had been called upon them by a witch or wizard, or by a person who was jealous of them. In relation to metaphysical causes people went to a traditional healer.

Many stated that leprosy was infectious and could be transmitted through *jutho* (a person's food leftovers), using the same eating utensils, sexual intercourse, and being in proximity to the person affected. Another naturalistic cause was that people believed their disease could have originated from within the body, because their blood was perceived as damaged, bad, or impure. Weakness due to old age or hard work, and having many worries due to poverty were also cited as causes of leprosy. The naturalistic cause was most often mentioned in combination with the physical separation within the family and the social stigmatization of

persons affected by leprosy. People who believed that their disease was contaminating mostly stated that out of fear of transmission, others would ask them to stay away and would isolate them eventually. Remedies related to this cause were either treatment sought at the traditional healer, or at a medical practitioner.

Only two persons suggested germs as the cause of their disease and both went to a private practitioner. The results of the analysis show that people do not have to believe in germs as causes for their disease in order to seek and continue medication at the health post. The majority believed in both a metaphysical and naturalistic cause and stated that they had faith that the medicines could cure them.

MEANING OF MEDICATION AS A STRONG MOTIVATION TO ADHERE TO TREATMENT

Leprosy medication was perceived as something very important and as a way of preventing their disease from becoming worse and visible. In addition, it was perceived as preventing (further) stigmatization. These interpretations of the leprosy medicines motivated people to continue treatment. Some experiences with their disease and its treatment reinforced this motivation. However, other experiences with their disease and its treatment influenced their intention to complete treatment negatively.

A strong motivator to continue medication was their understanding of *Kustha Rog*. The interviewees believed the medicines could cure visible symptoms and especially wounds, or could prevent (further) development of those visible signs of the disease. This belief in the efficacy of the medicines was reinforced when they experienced a reduction in their symptoms. Another experience that strengthened people's belief in the efficacy of the medicines was their observation that others had been released from treatment after their disease had been cured and this motivated them to continue treatment.

However, other factors related to treatment could influence this intention to continue treatment in a negative way. Some people reported how after one year the quality of the services at the health post where they collected the medicines, declined and how after some time they 'had no more patience and stopped taking the medicines'. Other people reported risks that were related to the medicines they had to take. The interviewees reported two such 'risks'. One was the severe side-effects experienced. Most of these were regarded as problems they had to cope with. However, if the side-effects became more severe, some believed that the medicines, and thus the care delivered by the health post were unsatisfactory and reconsidered their decision to continue or not with treatment. The second 'risk' experienced was the risk of exposure. Many people tried to hide their disease. Visible symptoms, monthly visits to the health post, the blisterpack with the medicines, and for some their skin turning black due to clofazimine, were all things they wanted to hide and were seen as triggers that could lead to exposure and thus could endanger their social position within the community and family.

AFTER EXPERIENCING SIDE-EFFECTS THE MAJORITY DO NOT SEEK HELP AND SOME DISCONTINUE TREATMENT

Another category of meanings that influenced the way people dealt with their disease and their treatment were the side-effects experienced. Many people interviewed had experienced side-effects. For the majority, these were only minor and not so troublesome. These often

occurred only once a month after the full dose of rifampicin (600 mg) and clofazimine (300 mg), and were side-effects such as slight weakness, slight stomach pains, and a slightly hot and dizzy feeling. Some experienced more severe side-effects such as black pigmentation, extreme weakness, vomiting, severe stomach and 'gas' problems, fever, and swelling. These people described how their side-effects had affected their lives. The different interpretations, the impact of the more severe side-effects and their significance for adherence to treatment is discussed below.

Blackness as a trigger to exposure

Some side-effects were perceived as triggers to exposure and increased people's fear of stigmatization. The black pigmentation due to the clofazimine that patients with multi-bacillary leprosy have to take was called 'blackness' by our informants. In a country where a fair skin is perceived as beautiful and very desirable, black skin pigmentation was of extreme concern. In managing expected stigmatization, many people concealed their disease. They feared that other people would notice them becoming black and would ask questions. Although blackness was not generally associated with leprosy, they did not want to attract other people's attention. Too much attention would lead to the exposure of their disease and thus to negative community behaviour. Experiencing blackness could influence people's decision to discontinue their treatment. For some people stopping their treatment was a way of managing potential stigma. Another interpretation of blackness that could be a reason for discontinuation of treatment was that people perceived their skin becoming black as the development of a second disease. One person felt that her blackness was a separate, dangerous disease. She believed that another woman had died due to this blackness. As she believed the medicines not only caused blackness, but that she could also die from it, she discontinued her leprosy medication.

Side-effects that made it difficult to work

Side-effects could also be perceived as signs of the disease that were caused by the medicines and that made it difficult to work. Many informants stated that after they had started taking their medication they had become weak, or that the medicines caused dizziness, stomach, and 'gas' problems. These side-effects could range from mild to severe. It is well known that multidrug (MDT) regimens can cause gastrointestinal problems, drowsiness, dizziness, and weakness. If these side-effects made it difficult for them to live a normal life and made it difficult for them to work, interviewees still felt they had no choice but to try to continue working. Only two persons who experienced these side-effects decided to discontinue their treatment.

Side-effects seen as an acute episode of the disease

A third interpretation of side-effects was that they could be seen as an acute episode of the disease. Also, this interpretation had an effect on the way people dealt with the disease and its treatment. Some side-effects occurred suddenly and lasted for a certain fixed period. Those mentioned were swelling; fever; skin peeling off; wounds; and blisters that suddenly appeared. None of the people who had experienced these side-effects knew what had happened to them and the vast majority waited until the next medicine collection day to discuss this problem. They believed the medicines had caused these side-effects. People who

had developed swelling perceived this as an acute state of the disease, which necessitated care. They had lost faith in the expertise of the health worker and therefore went somewhere else for treatment and did not return to the health post where they were registered.

PEOPLE'S DEFINITION OF CURE RESULTED IN A STRONG MOTIVATION TO CONTINUE TREATMENT

People expressed very clearly what cure meant to them and how their definition of cure had motivated them to continue treatment. They defined cure as 'symptoms that had diminished and disappeared after completing the course of treatment as advised by the health worker'. If symptoms persisted they felt their cure to be incomplete (29 defaulters and 32 RFTs) and desired to continue with treatment. Continuing symptoms were given as: numbness; *jhum jhum* feeling; patches; weakness; wounds, and on occasion even deformities. As long as symptoms persisted, most informants wanted to continue medication. After being informed by the health worker that they were cured, some people were either able to convince the health worker to continue supplying medication or they went to another health post. Some of the defaulters with persisting symptoms and who had discontinued treatment due to reasons related to the quality of leprosy services⁵ desired to complete their treatment.

Another aspect of cure that, however, none of the informants discussed was the possibility of their social integrity being restored in the village. Some reported that the negative community behaviour had ceased and was acceptable at the time of the interview, but they feared actions would re-start as soon as any symptoms re-appeared. They described a kind of 'wait and see' phase, as if to suggest that a total social cure was not feasible.

Conclusion

The way people interpret leprosy and its treatment influences their way of coping with the disease and thus their help seeking and adherence behaviour.

For the health workers, early recognition of symptoms is important. However, the interviewees did not recognize the minor symptoms of leprosy as leprosy and sometimes did not even regard them as symptoms of a disease which needed care. Many expected that minor symptoms would disappear by themselves. The interviewees reported to the health post as soon as they perceived their symptoms as severe enough to seek help. Nishimizu *et al.*¹⁰ reported a study conducted by Dhakal in which it was found that people in Nepal perceive illness as an inability to work, or as the presence of a debilitating condition. My study agrees with that of Dhakal in that people seek care only after the symptoms become more severe. Robertson *et al.*¹¹ found that not recognizing the early symptoms result in a delay in attendance at the health post. Here a tension exists between the understandings of early reporting between the health worker and the person involved. Although people went to the health post as soon as they perceived their symptoms serious enough to seek care, some reported being scolded when they reported to the health post with more advanced leprosy. Health education about the first symptoms of leprosy may result in people recognizing these as leprosy and coming to the health post for treatment. At the same time it could happen that the stigma attached to the advanced stage of leprosy consequently becomes attached to the early symptoms of leprosy. Health education about

the early symptoms of leprosy has to be carefully developed and given in order to prevent stigmatization of the early signs of leprosy.

The use of different names for leprosy is also recognized by other researchers,^{9,12,13} although these studies do not explain how and when these different names are used. The results of this study show that behind these different names different types of explanatory patient models exist. During the consultation, it is important to examine which local word for leprosy people use and explore which meaning this word has for them. If people use one of the words which refer to the *Charma Rog* type of explanatory model the health worker must be aware that the person affected may deny having *Kustha Rog* and consequently decide to discontinue treatment.

While analysing people's experiences with side-effects, it became clear that the interviewees reported side-effects that are not clearly described in the medical literature. Although not all side effects were experienced as a burden, it made life and treatment continuation more difficult. Due to time constraints and busy clinics, information on side effects was rarely given to the interviewees, who surely need (more) information on any side-effects that can develop. This study demonstrated not only that many interviewees said that they had developed side-effects, but it also showed the importance of the meanings these side-effects had for them and how it influenced adherence to treatment.

A difference exists between the understanding of cure by the health worker and by those affected by leprosy. For most interviewees 'to be cured' is to become as you were before you had the disease leprosy. As leprosy is mainly associated with wounds and deformities, it is understandable that people doubt that it is curable, so that if symptoms remain they want to continue treatment after the health worker has released them from treatment. Other studies obtained similar results.^{9,14,15-16} For most persons affected by leprosy 'to be cured' is to become as you were before you had the disease.¹⁶ More information is needed on the implications of symptoms remaining, the meaning of 'social cure', regaining social position in the community, and the possibility of the disappearance of the stigma.

Patients and health professionals can have different types of explanatory models. Kleinman⁴ uses the distinction between disease and illness. Explanatory models of medically trained people tell us something about how they understand and treat sickness. Here Kleinman uses the term 'disease' to refer to a malfunctioning of biological and/or psychological processes. The models of the patients and their families tell us something about how they make sense of episodes of their sickness; here he uses the term 'illness'. Patients seek not only symptom relief but also personally and socially meaningful explanations and psychological treatment for illness. The explanatory patient models are shaped by an interplay between the person, the illness and the culture or environment. The differences in the interpretations of the disease and its treatment that existed between the health worker and the person affected were rarely discussed between the two and this resulted in people remaining with unanswered questions and worries. In some cases, the difference in interpretation caused people to delay in seeking help, or to re-evaluate their decision regarding treatment continuation. Health education has to include the major signs and symptoms of leprosy, means of transmission, side-effects, definition of cure, needlessness of segregation (isolation) and the cause of wounds. What we should not forget, however, is that in the consultation between the health worker and the person affected, it is not only important that health education is given, but also that people's understanding of their disease and its treatment is explored and discussed. During consultation information should be shared between the health worker and the person affected. Training in better communication skills for health workers could include more attention to the people's perceptions of leprosy and its

treatment and to their fears and social exposure. Only in this way, can we understand what it means for individuals to have leprosy, to take treatment regularly and prevent them from actions that are undesirable from a medical point of view.

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