

**Leprosy: A Study of Identity through a “Marginalized”
Population**

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I would like to dedicate this paper to all leprosy affected people and everything that entails. Your bravery in the face of hardship is inspirational.

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Introduction

People of all different cultures use identity as a way of mediating with surrounding institutional structures and personal communities. Identity however, is not a concrete idea but a multidimensional and dynamic condition. For communities of so called "marginalized people" an identity perceived or created from the outside and imposed can have drastic implications on a person's capacity to act as an agent. Stefen Ecks argues for the value of ethnographic study from the point of view of the marginal people, going on to say that "this is of critical importance since marginality puts health most under stress when it is clearly and steadily perceived in everyday life" (199). I have studied the dynamic of illness and identity in populations of people living with leprosy in the Kathmandu Valley. By using case study, participant observation, textual research, visual documentation as well as formal and informal interview I have attempted to investigate Nepali people's (both living with and not living with leprosy) perceptions of leprosy and asked "Do people living with leprosy discard ethnic and caste identities and instead create a new sense of belonging based on their physical condition?" and if so "Does this lead to a new culture surrounding leprosy"? I have gained some understanding of the complexity in identifying with illness, from a population generally classified as "marginalized" and how that identity affects one's capability to cope with disease, interact with broader communities of people, and assert for personal needs.

Under the supervision of Peter Moran, I have looked into how people living with leprosy understand identity and culture through various organizations

and hospitals in the Kathmandu Valley. Leprosy is an endemic disease in Nepal and has therefore spurred the creation of a number of private and government funded treatment centers, hospitals, and even a leprosy colony in the valley. I concentrated my research in three areas: the hospital, the NGO, and the government funded leprosy colony. Historically leprosy is a disease that has been controlled by attempting to “keep leprosy patients away from the community in hospitals, sanatoria or rehabilitation colonies” (Upadhyay v). I believe the movement of patients from villages to central and urban containment, compounded by the societal stigma associated with leprosy may have profound impacts on a one’s sense of identity. Nepali identity is extremely complex but often bound to ideas of ethnicity, caste, family, religious tradition and language (Tourin 9-28-07). Currently, in the Janajati movement, Nepali people are using ethnic identities to unite and fight for political rights (Moran 9-5-07). In a personal conversation with Peter Moran I found however, that at a particular rally organized by a Nepali indigenous people’s group there was also a group of visibly disabled people rallying together. It made me wonder if such a group exists for people living with leprosy, and if people living with leprosy visibly, and also more subtly discard ethnic and caste identities to create a new sense of belonging. Is there, in fact, a culture of leprosy that is in turn created by this new sense of identity and are there people living with leprosy who do not fit into this culture or are excluded from it? Furthermore, if a new identity is present, how are lepers using this identity to act as agents and assert for needs? I also found it pertinent

to ask if there are certain ethnic or caste groups that are disproportionately affected by leprosy.

My research is framed in the discourse of marginality that Ecks presents. Marginality can not be defined as a static condition, but Ecks argues that marginality is socially constructed and perceived differently from many viewpoints and that perceptions of marginality have profound affects on health (208). Leprosy "patients" are considered "marginalized" perhaps because of poverty or stigma surrounding the disease and a discourse of marginality which always relates "the leper" to a central, non-marginalized agent. A quote from Ecks reads, "Marginal people are often represented as being in need of more drugs, more doctors, and more technology; as the 'patients' of 'central agents'. Yet certainly such people have their own agency, their own moral discourses, and their own notions of marginality. Who counts, after all, as 'marginal', and according to what criteria? Where are their voices, what are their experiences? Do they in fact perceive themselves as marginal? Do they have their own discourse of marginality, their own ways of coping? And if so, do such projects correspond to projects initiated at the 'centre'?" (201). I have kept in mind the discourse on marginality and its close links to the discourse of identity when approaching my research and have tried to investigate some of the questions that Ecks presents in my study of leprosy and identity in the Kathmandu Valley.

What the current research has yielded is a realization that identity is much more complicated than initially anticipated, and people living at Anandaban Hospital, Kokhana Leprosarium, or Shanti Sewa Griha identify in different ways

at different times and in different contexts. Furthermore, the way the institutions identify people using their services influences individual identities while simultaneously individual identities influence institutions. At times I also sensed disconnection between the way the institution identified those living there and the way the individual spoke about him or herself.

Methodology

I began by getting an idea of the various organizations set up to deal with leprosy in Nepal. I set up interviews with the Ministry of Health's Leprosy Division in Teku, the administration at Anandaban Hospital in Tikabhairab (as well as their weekly clinics at Patan Hospital), the government funded National Leprosy Relief Association (which runs the Kokhana Leprosarium) in Maharaj Ganj, and the German-funded NGO Shanti Sewa Griha at sites in Gaushala and Budhanilkantha. After building some rapport and getting much needed background information I was able to meet with about 22 people (9 women and 13 men) living with leprosy or its after-effects in the Kathmandu Valley, and talked to each person about his or her life and what living with leprosy, and for some also living in an institution, meant to him or her. 8 people were of Chettri caste, 4 Brahmin, 2 Tamang, 2 Dalit, 2 Magar, and 1 Rai. The individuals I spoke with were from various regions of Nepal and one man was from India and came seeking treatment in Nepal.

I did face some limitations and challenges in my research. For one, many of the interviews with leprosy affected people were conducted in Nepali with the assistance of a translator. When dealing with obtuse topics like identity and

feelings, I had to be very careful not only to word questions in a way that made sense to the individual, but also to try to correctly translate the exact *way* in which each person answered questions. This proved difficult, especially when trying to translate a poem, because many Nepali phrases do not translate well into English.

I also solicited the help of my advisor, Peter Moran and Dr. Ron Barrett in formatting pertinent questions. For example, instead of saying “were you discriminated against”, Dr. Barrett suggested I ask how often the individual visits his or her village and whether he or she eats with the same thali as other members of the family. I spoke with many individuals in a very short amount of time and therefore did not have as much time as I would have liked to build rapport with each person. Though many interlocutors were very eager to share their stories with me, there is always a possibility (because of the topic and nature of questions I asked) that an individual was answering questions in a way he or she thought I wanted to hear. I tried to (at least partially) overcome this barrier by carefully explaining my research to each person who I talked to (getting fully informed consent), and explicitly stating, “The reason I am doing this research is because I think it is important to hear people’s stories” and *not* saying “I want to hear about how hard your life is”.

The conversations I had with many leprosy affected people in different situations are an effort to couch the larger rhetoric against individual stories. Having the opportunity to be able to talk with many brave individuals who have faced extreme hardship with a great deal of resilience has not only contributed to the discourse on identity but has also (and perhaps more

importantly) humanized the widely misunderstood and stigmatized disease of leprosy.

Leprosy in Nepal: Brief Introduction to the Government Perspective

According to a 2007 estimate, about 224,717 leprosy cases have been identified worldwide. The number of new cases detected during 2006 was 259,017 (August 2007 Newsletter). To date, between 1 and 2 million people have become permanently disfigured from Leprosy (Song). Unfortunately, Nepal is one of four countries (including Brazil, DR Congo and Mozambique) that has yet to eliminate leprosy as a public health problem (August 2007 Newsletter).

According to the World Health Organization, elimination is defined as a prevalence below 1 per 10,000 people. According to the Ministry of Health and Population's Annual Report, during the 2005/2006 year "a total of 10,113 cases were registered for treatment in Nepal" putting Leprosy in Nepal at a prevalence rate of 1.65 per 10,000 people (11). The highest number of new cases has been detected in the Central Development Region followed by the Eastern Development Region. The Midwestern Region showed the lowest number of new cases (Annual Report 12).

While the Health Ministry strives to provide a decentralized public health care, this data could be skewed as a result of centralized treatment and monitoring as well as reduced stigma surrounding the disease (and therefore increased willingness to seek treatment) in the central region. To create more awareness, the Leprosy Division has increased media campaigning as well as capacity

building at the grass roots level of sub-health posts. All media content is standard throughout Nepal and distributed in three languages of Nepali, Maithili, and Bhojpuri (Bhattarai 11-12-2007). Capacity building includes Comprehensive Leprosy Training--a one week course in diagnosis, treatment and management of Leprosy (Bhattarai 11-12-2007). Furthermore, all leprosy treatment and services are to be provided for free (Bhattarai 11-12-2007). The government considers the trained manpower, good network of referral services, regular review meetings, uninterrupted MDT (medication) supply, and elaborate data base "of good quality" to be strengths in the effort to eliminate leprosy in Nepal (Annual Report 16). With regard to the MDT, however, several leprosy affected people I spoke with expressed a need to stay in the Kathmandu Valley because sufficient treatment was not available in their villages. The Annual Report does express a need to increase MDT services in low/non endemic areas by the end of 2007 (15).

Governmental weaknesses include low motivation of peripheral staff and a centralized decision making process which they plan to tackle with increased "refresher training, supervision, and monitoring" (Annual Report 15-16). According to Mr. Sushil Bhattarai of the Leprosy Division of the Ministry of Health and Population, because of the integration of leprosy treatment into the general health care system compounded with a realization that community awareness and community based rehabilitation are important factors to ending discrimination against leprosy, "the degree of discrimination has decreased" and "people with leprosy are no longer kept in isolation" (11-12-2007). While many of these practices seem to be a positive step in the right direction, I worry that

standardizing awareness and distributing material in only three languages (though three languages is much better than only Nepali) might further contribute to homogenization of the "leper" by mainstream society as in some ways suggests that every "leper" has the same needs and not that specific communities have unique ways they view the world, relate, and think about health.

What It Is

Leprosy is a chronic disease caused by the bacillus, *Mycobacterium leprae*. It was discovered in 1873 by the Austrian scientist Armaur Hansen and is therefore frequently referred to as Hansen's Disease. The bacteria mainly affects the skin and nerves, and if untreated can "permanently damage the skin, nerves, limbs, and eyes" (Song). The treatment for Leprosy is MDT or multi-drug therapy which consists of dapson, rifampicin, and clofazimine, and most patients require treatment anywhere from 6 months to 2 years (Dixit 119). Early symptoms of Leprosy are "reddish or pale colored skin patches" (Song) which may become anesthetic. The bacillus attacks nerve endings and destroys the body's ability to feel pain and injury. Self care for anesthetic limbs is extremely important because infection can spread to the bone, "[resulting] in tissue loss" (Song). Mr. Shresta of Anandaban Hospital explained that the limbs contract, making very simple tasks "like eating daalbaat with hands" (which is a common Nepali practice) virtually impossible (11-13-2007). While Leprosy is known to be only mildly contagious, the "exact mode of transmission has yet to be proven" (Barrett 217). According to Barrett, "evidence suggests a hereditary component to this

susceptibility" (217) but it is also suspected that *M. leprae* can be transmitted through "droplets from nose and mouth, during close and frequent contacts with untreated, infected persons" (Song). Leprosy is **not** transmittable while a patient is receiving treatment or after treatment has completed. However, Barrett who has done research with leprosy affected people in Banaras, India puts it well saying, "in contrast to the bacterium, the social mark of leprosy in India is highly contagious". The same goes for Nepal. According to Pradeep Failbus, former Anandaban Leprosy Hospital superintendent, "The leprosy problem does not end with medical care because the real challenges start after the patients leave the hospital" (IRIN 6-2-2005).

"In my village people hate"

When Til was 13 years old she was sent to her uncle's home in Western Nepal because she had leprosy. Her aunt did not want her staying there and one day gave her a roti and told her to leave. Til had seen how others from her village with leprosy had been banished to the jungle so she ran away from her uncle's home. She hasn't seen anyone from her family since and is currently living in the Kokhana Leprosarium. She is 74 years old and has lost both legs to leprosy. "In my village people hate", she says. This makes her very sad (Til 11-19-2007).

Aiman found out he had leprosy 5 years ago. He got pills from a local health post near Dhulikel but when he started taking them in his village his friends ran away from him. "They would close windows and doors", he says. His son began to treat him very badly and with other villagers planned to build a house

and isolate him. After he died, they were going to collapse the building.

Eventually his son gave him a choice of living in a cave, the house, or on the bank of a river nearby. Aiman found Anandaban Hospital. After treatment, Anandaban encouraged him to go back to his village but he did not want to go there because of the way people had treated him. He wandered homeless for one month until he found Kokhana Leprosarium. He is 57 years old. He hasn't seen his son since he came to Kokhana. "They don't love me so they don't come to visit me" (Aiman11-19-2007).

Mithu is a 23 year old woman from Bhaktapur. She was only 15 years old when she contracted leprosy. She was discriminated by her husband and family. Her husband left her to marry someone else and she does not keep in contact with him anymore. She is currently living alone in Gottatar. She has no family now. She has been involved with IDEA Nepal, an acronym for Integration Dignity and Economic Advancement, for 8 years (Mithu 12-1-2007). IDEA is an international organization dedicated to integrating people affected by leprosy who are discriminated by society--the main aim being "total human rights" says Mr. Binaya Sharma, the organization secretary. According to international guidelines, the chairperson, treasurer and secretary of IDEA must be living with leprosy or affected by leprosy in some way. I also noticed that many of the executive members were leprosy affected. Both of Mr. Sharma's parents are living with leprosy, and Sharma's involvement with IDEA Nepal as a way to "stay, think and work for [his parents]". "That is my duty in IDEA Nepal" (Sharma 12-1-2007). Through IDEA Nepal, Mithu hopes to share her vision and thoughts to

help others who are leprosy affected (Mithu 12-1-2007). Through IDEA, I have realized that some people affected by leprosy in Nepal do not only identify with other people living with leprosy locally, but also with a broader international movement supporting human rights. On January 29, 2007 the Global Appeal to end discrimination and stigma against those affected by leprosy was signed in Manila. 16 leprosy affected people from around the globe signed the appeal, which included a demand for an end to silence, discrimination, and an increase in awareness of "misguided notions about leprosy" which still persist. One Nepali, Parawati Oli, was among the signatories (February 2007 Newsletter).

According to Yohei Sasakawa, the WHO Goodwill Ambassador for the Elimination of Leprosy, "even after people with leprosy have been treated and cured, the stigma of the disease can undermine their basic human rights, in particular, the right to work, to marry, and to receive an education." He goes on to say that those affected by leprosy are not the only potential targets of discrimination, but "tens of millions of their family members and relatives also face ostracization" (August 2007 Newsletter). In "The Stigma of Leprosy in Northern India", Dr. Ron Barrett writes, "friends and relatives of people with Hansen's Disease risk severe social and economic losses for their affiliations. Consequently, many Indian families would rather banish their diagnosed relatives to a distant town or city than risk discrimination against the entire household" (217). Mr. Battari also adds that "in the village, illiterate have more problems because people and family members sometimes try to manipulate them because of their leprosy" (11-12-2007). In the last month I have repeatedly heard the phrase

"in the village people hate" from both administrators of leprosy-related institutions as well as numerous leprosy affected people. This may be tied to the idea that many people look at leprosy as a God-given punishment (Sharma 11-13-2007). Mr. Chiranjivi Sharma, a counselor at Anandaban Leprosy Hospital, frequently hears patients say "I have been cursed" (11-13-2007). Bhagwati is 23 year old woman who hid her disease from her husband and his family. She went to a Shaman who told her that she had upset the snake spirit—"naag laagyo". She thought perhaps she had done something to anger the snake and therefore she got sick. In the village, "they will not say you have kushta rog", only "naraamro rog" (Bhagwati 1-27-2007) which means "a bad disease" in Nepali. This signals an unwillingness to talk about leprosy, a silence that only contributes to discrimination.

Unfortunately, these beliefs tend to cause people to prolong treatment, which increases development of anesthetic limbs. "Because of the ever-present threat of injury to anesthetic limbs, people with Hansen's Disease neuropathies must be hyperaware of their bodies in relation to their surrounding environments" (Barrett 218). While preventive measures are straightforward, they are hard to maintain as "they become formidable under the conditions of extreme poverty and demoralization that is common among people who are publicly branded as 'lepers'..." (Barrett 218). The physical deformity associated with leprosy only adds to stigma surrounding the disease. To make it worse, many people who do have the courage to seek out MDT treatment develop side-effects to the medication, otherwise known as a Type II reaction or ENL. This type of reaction

is associated with nodules on the skin, which later become bright red or black spots (Manat 11-14-2007). The darkening of the skin is another problem that people affected by leprosy have to deal with because in Nepal, fair skin is considered preferable and more beautiful. Dr. Kishori Manat of Anandaban Hospital also says that she notices much more depression and low morale among patients that exhibit Type II reactions (11-14-2007). At the Patan Hospital Clinic, Mr. Sharma informed me that one young girl he had seen the previous week was “crying bitterly” because as soon as she had been diagnosed with leprosy her mother refused to eat on the same thali, or plate as her. Barrett describes this as a common familial reaction to leprosy saying that it falls in the realm of “ritual pollution taboo” (222). According to Madan Ghimire, a noted leprosy specialist, in Nepal “even educated people have strong prejudices against the leprosy affected” (IRIN 6-2-2005).

Leprosy.Identity.Marginalization

Traditional beliefs about leprosy as a punishment, physical deformity, social exclusion by spouses and family, and added to a history of isolation have really intensified societal stigma against leprosy. I believe this stigma against people with leprosy strongly contributes the tendency of those suffering from the disease or after-effects to discard some traditional views of identity in favor of identities which surround leprosy. It creates an atmosphere of solidarity, and as in Mithu’s case even motivation to work under an international organization dedicated to fighting for the basic human rights of other people living with the

stigma of being a “leper”. This sort of organization creates a space in which people can talk about leprosy as more than just a “naraamro rog”. In fact, in 1998 IDEA Nepal even recognized the negative associations with the term “leper”, quote:

“We recommend that words like ‘kori’, ‘kushtarogi’ and ‘maharogi’, which define people by their disease be eliminated from our vocabulary, and that expressions such as ‘kushtarogi’ or ‘birami’ no longer be used to describe persons once they have been medically cured of the disease. If it is necessary to mention a person’s association with leprosy, the term ‘person affected by leprosy’ is strongly recommended” (<http://www.humanrights.org.np/event.htm>).

Dr. Yozo Yokota, a Profesor of Law at Chuo University in Tokyo says that these words create discrimination against a particular category of person. “Such categorizations are a creation of the human mind” he says, and “have nothing to do with the objective character of a person (August 2007 Newsletter). Society tends towards categorization and labeling of individuals (Moran 12-4-2007). I believe these labels imply an identity, which although constructed, has serious social implications (Graif 12-3-2007). Ecks states it well saying “stigma is shown to be a thoroughly relational concept” (200).

For many people I met, this categorization, varying degrees of isolation, and subsequent bodily disfigurement forced withdrawal from mainstream society. As Dr. Yokota states, many times leprosy affected people “congregate with other affected persons but as a group feel isolated from the rest of society” (August

2007 Newsletter). Mr. Raneshor Neupane, a leprosy affected individual, frequently refers to others living with leprosy as “brothers” and “sisters” in a poem he composed to try to understand the disease and address the misconception that leprosy is a curse (11-21-2007). I also read about two different leprosy communities outside of Nepal in my research, and a brief comparison may lend credence to the idea that to some extent older people living with leprosy identify similarly.

With regard to leprosy being a curse, the Goodwill Ambassador, Mr. Yohei Sasakawa, noticed that on a visit to the village of Ban Somsanouk in Laos, “some people still think that leprosy is divine retribution and that disease originates from within” (February 2007 Newsletter). Furthermore, in 1865, King Kamehamena V ordered incurable leprosy victims on the Hawaiian island of Molokai to be removed from the general population, and “many Caucasians took this as divine punishment for what they viewed as the promiscuous Hawaiian lifestyle” (Lassalle). Also, I noticed that Paul Harada, a long time resident of Molokai, when given the option to leave said “I’m all crippled. What am I going to do outside? (Song). This sentiment was reiterated in many of the leprosy affected people I spoke to, including Yam who said “I can’t do anything” (11-28-2007), Aiman who comments “I *used* to do a lot of things” (11-19-2007) and Janaklal, who said “If you don’t have legs, if you don’t have hands, what can you do?” (11-27-2007).

In his poem, Mr. Neupane also parallels emotional and physical pain, saying “If you are burned it hurts just as when someone hates you feel pain” (11-21-2007), a comment which adds to the multi-dimensional nature of identity and how people perceive themselves. In the book Culture Health and Illness, Cecil Helmen addresses the issue of pain, saying “because of this biological role, it is sometimes assumed that pain is culture free—in the sense of being a universal biological reaction to a specific type of stimulus” (183). This is interesting because a number of people I spoke to, though they had lost most sensation in parts of their limbs (like Mr. Neupane), mentioned feeling pain. Helmen says, “The Western model of pain as mainly a physical event may be inappropriate” continuing that “North Indian cultural patterning depicts pain not as a single, fixed entity but rather as a fluid, context-sensitive constellation of meanings” (184). Pain is associated differently at different times, sometimes physically, emotionally, socially, or spiritually, and these factors in turn “all inform identity in different ways”. I agree with her that even in the case of people living with leprosy “cultural factors in terms of attitudinal variables, whether explicit or implicit, do indeed exert significant influences on pain perception” (184).

When viewed in the larger discourse of marginalization, all of these factors make significant contributions to the degree with which a person views him or herself as “marginalized”. With no other opportunities for social integration, “it is in the interests of the discredited to maximize their out-group identity” (Barrett 225). Barrett goes on to say that “people ‘learn to be lepers’ by being socialized into discriminatory models around them” (225). Karin Polit

argues that “marginality must always be seen in a specific context” (Ecks 200), which is clear when one addresses the “leper” within the larger context of society vs. how leprosy affected view themselves within a smaller community of a leprosy colony or treatment center. Mina, a 68 year old woman affected by leprosy since the age of 13 and who has been living at Shanti for the past 8 years commented on how she was able to do more “inside” the institution than “outside” when she has to deal with “normal people” (11-28-2007). I believe that for people who have spent a great deal of time in isolation, perceived marginalization often times is less “inside” than “outside”.

Khokana Leprosarium:

The 160 leprosy affected people living at Khokana Leprosarium are supported by the National Leprosy Relief Association, or NELRA (Brochure). In talking with Mr. Viddur Basnet, I found that during the 1857 Rana Regime, Khokana Leprosarium was built far from the village in a separate place where “wind does not come” because people were afraid that leprosy could spread through the air (11-30-2007). Currently NELRA supports two different leprosy colonies, Khokana as well as the Malunga Leprosarium in Pokhara.

In 1988, NELRA started a leprosy patients resettlement program and to date 257 leprosy patients “from leprosaria, streets, and temples have been resettled by building 176 low cost homes” (Brochure, Basnet 11-30-2007). At Khokana, NELRA has a vocational training center which, with help from the German Leprosy Relief Association, “imparts training on Carpentry and Mechanical trades to 25 trainees each year” (Brochure). I had the opportunity to

see the training center which, according to the manager Mr. Kulbikram Lama, received up to 80 applicants last year. The boys who participate in the training center must be between 18 and 30 years old, affected or infected by leprosy, and “able” (Lama 11-19-2007). Siva, an 18 year old boy from Jhappa contracted leprosy when he was 5 years old. While his parents worried about his health, others in his village behaved “weirdly” towards him when they found out he had leprosy. With training from NELRA he will be able to get a job though “not necessarily in [his] village” (Shiva 11-19-2007).

NELRA also provides education for children with parents affected by leprosy under the philosophy that “children capable of earning will not be the burden of their parents” but instead “an active citizen of the country (Brochure). They have boys and girls hostels (Basnet 11-30-2007) as well as a scholarship program for patients and children attending school in their native villages (Brochure). Finally, NELRA operates an awareness campaign through calendars, pamphlets, posters, bulletins, television, and radio programs. Their message is, “All human beings are born free and equal in dignity and human rights. Leprosy is curable, Early treatment prevents disability. Treatment is available in all hospitals and health-posts. Free treatment and free medicine is the privilege to all patients” (Brochure).

While I found no study that shows certain caste groups of people to be disproportionately affected by leprosy, according to Mr. Basnet, people with Mongoloid features (like Tamangs), tend to contract more of the infectious type of leprosy than those with Aryan features (11-30-2007). This observation seemed

to be based on the caste make-up of Khokana, which according to a roster is approximately 39 Tamang people, 33 Chettri, 20 Brahmin, 15 Magar, 12 Dalit, 8 Newar, 5 Gurung, 4 Rai, 3 people of an “Indigenous” group, and one Tharu person. 77 people claimed social exclusion as their primary reason for coming to Khokana, 54 poverty and three people had come with a parent. Also, only 18 people living at Khokana currently own land (Roster).

At Khokana, the people I spoke with had been living at the Leprosarium for most of their lives, with the exception of two young men who were studying at the Vocational Training Center. I noticed Khokana to be a large compound tucked away in the background of a beautiful green rice paddy landscape. Based on the length of isolation, I believe that many people at Khokana have created a somewhat new life based on these concepts of “inside” and “outside”. Though not living in the best of conditions and surviving on a mere 300 rupees per month (with which each person buys his or her own vegetables, oil, kerosene, and masala), to me Khokana seems like the only home many people living there ever knew. Thuli, a 62 year old woman from East Nepal who has been living at Khokana since she was 10 year old says she has many friends at Khokana, adding “we are same” (11-19-2007), in a way that made me perceive she thought it was common sense that everyone in Khokana should be friends by virtue of a shared disease. However, tears stream down her face as she adds that she never feels like leaving “this place” because she has no one outside of it (11-19-2007). I felt as though some of her sadness stemmed from the death of her husband, a leprosy affected man whom she married at Khokana.

Many of the residents of Khokana have married with other leprosy affected people inside the institution. Mr. Hamel, one of the administrators says that NELRA encourages marriage within the community, “so they can help each other out” (11-19-2007). The choice to marry might suggest that residents have shrugged off traditional Nepali marriage for a more untraditional, equal partnership. On the other hand, I found out that in Khokana, all of the people who were married only married with others from their own caste so in some ways the non-traditional marriage was still bound to a very traditional caste hierarchy. Furthermore, I am unsure as to whether NELRA actually imposes the ideas of marriage or simply makes a suggestion. I have, however, heard that they do not necessarily encourage same caste marriages (Graif 12-3-2007).

When talking about how perceived marginalization is less “inside” than “outside”, these terms become very interesting because of the possible shift in power dynamics they imply. Inside the Leprosarium, the people living there could be considered central agents while the outside society takes on the roll of the “other”. Earlier I mentioned how many leprosy affected people suffer from depression as a result of societal stigma. According to Ecks, “depression is a form of marginalization that can only be truly overcome by rebuilding social ties” (205). Khokana is a place where people have been able to rebuild these ties through marriage or simply a new community of people with a shared background.

Dhag Bahadur is a very pleasant 48 year old man from Sindupalchok who has been living at Kokhana for 31 years and originally came with his mother who

was also leprosy affected. He has lost both his hands and feet to leprosy. He had married inside Khokana though his wife passed away three years ago. Initially his family did not want to stay with him, they hated him and “didn’t care” (11-19-2007). However, now things are much better with his family, and he has been back to his village many times. His sister-in-law treats him well, and when he goes to her home they eat with the same thali. Dhag’s case is extremely interesting because while he has rebuilt social ties with his family, he prefers to stay in Khokana with “his society”. Even for traditional festivals like Dassain and Tihar, Dhag prefers Khokana saying “it is more fun to stay here during the holidays” (11-19-2007). Dhag exemplifies the concept that marginalization is highly dependent on perspective, and how both identity and marginalization are complex entities where at different times people move in and out of seemingly contradicting social roles in a fluid manner.

Anadaban Hospital

Anandaban Hospital in Tikhabairab was founded in 1957 by The Leprosy Mission International. It is the largest leprosy hospital in Nepal, serving as “the main leprosy referral [center] for the Central Region of Nepal”, and “employing 112 Nepalese and 6 expatriates in the hospital and associated projects” (tlmnepal.org). Leprosy patients of Anandaban receive free treatment, surgery, and wound care while local people can also come to the hospital for general health needs (11-13-2007). Additionally, Anandaban is very active in Community Based Rehabilitation (CBR) for people living with leprosy.

According to Mr. Kandel, Executive Officer of Anandaban, a huge part of this focus on CBR stems from a need to educate the general public so that early signs of leprosy are detected and people do not hide from getting treatment (11-27-2007). In many ways, Anandaban seems hyper-aware of the consequences of isolation and makes efforts to decrease the marginalization that many suffering from leprosy end up dealing with. Delayed treatment is often associated with a “low economic condition”, so “if we can do something for their livelihood this can be seen by others” and those people will say “He had leprosy. He is cured and he is doing something productive for his family” (Kandel 11-27-2007). Kandel adds this importance of “going home” (back to the village) for leprosy patients saying “it will be hard at first but with our support it may be easier” (11-27-2007). Kandel is also a member of IDEA Nepal and mentions the negative affects of discriminative laws in Nepal which make it very easy for men to divorce their wives and fosters an atmosphere of hate between spouses. An article about living with leprosy in Nepal reads “the situation is much worse for girls and women. They are frequently abandoned by their husbands and male relatives when deformities develop” (IRIN).

The aim of the Socio-economic Rehabilitaton (CBR) Program is :

“To develop self confidence, self respect and self dignity among the people of leprosy background, to make them able to look after their daily needs and earn for their living and finally settling them in their own communities as valuable members of society”

The program includes assisting with school fees, support for income generating projects (in animal husbandry, small shops, or workshops), skills development, support for low cost housing, and other miscellaneous activities (Brochure).

While Anandaban works to provide more than simply treatment and to address individual needs, it is a transitional facility and therefore most people do not stay for more than two years. Subsequently, I did not particularly notice that very many leprosy patients created identities within the institution. However with respect to changes over time in the attitudes of people affected by leprosy I learned a great deal. In Mr. Raneshor Neupane's poem "Leprosy Can Be Recovered", he mentions how in the very beginning Anandaban was merely a few huts where people of all castes had to live together in one room. "My stomach moves because the gross woman cobbler touched food", he writes, and worries that relatives might find out about the intermingling castes.

In the few times I visited Anandaban, I noticed people of various castes happily sitting and talking together. Nanda, a 77 year old man from the Sindhuli district tells me that when he first got leprosy he didn't tell anyone because, "In village people hate" (I heard again). People in his village still don't know (11-21-2007). When I ask him if anyone else (to his knowledge) has leprosy in his village, he definitively says "no". Then he adds that there was *one* woman. She was a Rai woman whose family had put her in an animal barn. Nanda, a Brahmin man, reached out to her and brought her to Anandaban Hospital. To the best of his knowledge she is now married and living at Khokana (11-27-2007). Nanda's story shows how exclusion forced by societal stigma has the power to overcome

some rigidities of caste hierarchy, even in many villages. Nanda, a man who himself has to bear the burden of discrimination in the village seemingly identified with this Rai woman enough to break through caste boundaries and forge an untraditional relationship by virtue of a common disease.

Shanti Sewa Griha

Shanti Sewa Griha, or "Peace Service Home" is a German (Shanti Leprahilfe Dormund e.V.) funded NGO which "helps poor, sick and leprosy affected people, handicapped and orphans" (brochure). With sites in Gaushala, Budhanilkantha, Sundarijal, and Tilganga, Shanti aims to provide free shelter, medical services and medicines, rehabilitation, vocational training, infrastructure to produce goods, school education, nourishing food and information about health and nutrition, education and childcare for leprosy affected and others in need (brochure). Together, Mr. Krishna Gurung (in-country coordinator of Shanti) and Ms. Marianne Grosspietch (foreign partner) started the organization in 1992 when many people with leprosy were begging near Pashupati temple (Gurung 10-18-2007). In the mission of transforming "beggars to givers" (Gurung 11-28-2007) Mr. Gurung and Ms. Grosspietch pursue an "all-encompassing strategy" of "creating self-esteem and dignity for *[Shanti's] people*, respect [of] people's indigenous culture and religion, awareness that all human beings have a responsibility to care for each other" and a spirit of "self-sufficiency and independence" (brochure). According to Mr. Gurung, a hospital is only "half treatment" and in Shanti he is "trying to give life back to *them*", to make "*[them]*

understand what the meaning of *their* life is". That is to say, people should not let their disability debilitate them, but instead should learn skills and make a contribution (Gurung 10-18-2007). Many of the people working or staying at Shanti have suffered the devastating after-effects of leprosy including loss of limbs, generally hands and feet. During a tour of the Gaushala site I noticed that in the workshop, all people affected with leprosy, polio, blindness, and other disabilities have work--either preparing briquette for sustainable fuel, sewing clothes, or making crafts and paper to be sold abroad. To the best of my knowledge, most workers are paid a salary of about 3300 rupees per month. According to Ms. Grosspietch, because of stigma in their home communities or need for education for their children, many leprosy affected people have sought refuge in Shanti (Grosspietch10-18-2007).

In 1993, Shanti bought 13,000 square meters of land in Budhanilkantha on the outskirts of Kathmandu. In addition to a health clinic, malnutrition center, nursery, a children's school, a kindergarten, and a playground, they have transformed this land into an "eco-village" consisting of organic vegetable gardens, fruit trees, and a poultry farm (brochure). I also noticed the active use of solar cookers and teaching kitchens. The kitchens are made of clay and resemble "traditional Nepali kitchens", which are used to teach mothers how to prepare nutritious meals for their children (Gurung 10-18-2007). The vision of this village seems to be a community where there is no place for idleness (Grosspietch 10-18-2007) but instead each person works for the benefit of the one another. The general philosophy and teaching style of Shanti is run on the Waldorf method

(Gurung 10-18-2007), a philosophy based on the idea of Anthroposophy which is a "European idealistic philosophy rooted in Aristotle, Plato, and Thomas Aquinas" (Mays and Nordwall). A Waldorf teacher looks to bring out the essence of each person "that is independent of external appearance" and instead promotes an "understanding of and appreciation for [each person's] background and place in the world" that is *irrespective of nationality, ethnicity, and race*. In other words, this philosophy of education strives to nurture respect for others by virtue of their humanity alone and also "enable students as fully as possible to choose and, in freedom, to realize their individual path through life as adults" (Mays and Nordwall). The biodynamic farming methods that the Budhanilkantha community employs are also

While Shanti's mission is good, it is extremely idealistic and at times (as would be expected in any such community) misunderstandings arise. For example, one of the volunteers noticed that after cleaning, some of the workers were throwing the soapy water onto the organic vegetables (10-18-2007). Additionally, when I asked Ms. Grosspietch what her biggest challenge was, she answered that the political situation has caused difficulties for Shanti. Because of Maoist influences, some members of the Shanti Community had been requesting higher wages and demanding contracts (Grosspietch 10-18-2007). According to Mr. Gurung, political turmoil has been good for the oppressed to speak out "but not in Shanti". To him, the people of Shanti are the most privileged. They used to be beggars on the street and now their children are in the best schools and they have shelter, food and work. "There is a difference between a private institution

(NGO) and a government one" (Gurung 11-28-2007). Mr. Gurung expresses a need for Shanti to systematize and feels embarrassed that operations in the village are not running according to the vision (Gurung 10-28-2007).

I point these instances out because when viewed through the discourse on identity, they illustrate how sometimes a vision, or identity imposed from one party may not match up to the ways those within the second party identify themselves and their lives. While I was not able to speak with any of the leprosy affected people living in Budhanilkantha, some personal experiences may shed light on the matter. In my Nepali family, I frequently noticed that after washing dishes, the soapy water would be thrown onto a tomato plant nearby. In Nepal, water is a precious and scarce resource which people are not keen to waste. To me, when taken into the context of "Nepali people and water", it does not seem exceedingly surprising that soapy water was deposited onto the garden.

Furthermore, I wonder if Ms. Grosspietch and Mr. Gurung's aim (through very Western concepts of Waldorf philosophy and biodynamic farming) to create a Shanti Community that exists outside of nationalism, ethnicity, and race (of course with respect to indigenous culture and religion) is really possible. As Mr. Gurung said, they eventually had to deal with the political problems though initially they had resolved to "do it [their] own way" and to "not allow political problems to be [their] problems" (11-28-2007). Shanti seems to use identity as a form of empowerment (Graif 12-2007) within an extremely unionized community. But do the people living within Shanti identify this way? Earlier I quoted Mina, a woman living at Shanti for the past 10 years. To some extent,

Mina seemed to identify with Shanti and its aim to create an environment of equality and empowerment saying, "In Shanti I can do some things, but outside it is difficult compared to another normal person. In Shanti it is not so difficult even compared with another normal person" (11-28-2007). On the other hand, when I ask her what she has learned from Shanti and she says "I have learned nothing from Shanti" and then adds "without Shanti maybe I would be dead" (11-28-2007). From these statements it seems Shanti is more a place of refuge than a community to find empowerment.

Yam, a 72 year old man who has been living with leprosy for 35 years and at Shanti for 10 years similarly commented that survival is difficult in the village and at Shanti amenities are available and therefore "I want to stay here". However, he goes on to say, "the people here aren't only friends! Here at Shanti we are like a family!" With respect to his leprosy, Yam says that sometimes he feels like leprosy is nothing--just a small disease. On other days it is a very strong and hard disease. "I had leprosy so I had to struggle". He also repeatedly uses the word "dukha", meaning hurt in Nepali, saying "I am poor and sad" (11-28-2007). These comments lead me to believe that in a certain context he also identifies with leprosy as a disease of the poor, the struggling, and the sad and therefore simultaneously connects with other people who have leprosy and also a broader group of struggling people. Furthermore, at certain times within one conversation he seems to both identify with and negate Shanti. To some extent he has left the notion of traditional Nepali family to create a new family within Shanti, and yet he does not talk of himself in ways aligned with the Shanti

vision. To add to the complexity, he says that during Dassain and Tihar he went outside Shanti to the Kali Mandir but also did Tikka for everyone within Shanti, as people there think of him as their grandfather (11-28-2007). Yam is an excellent example of how, when asking the question, do people with leprosy discard identities and create new ones, the answer becomes both yes and no.

Analysis

After talking to many individuals affected by leprosy as well as people from various leprosy-related institutions in Nepal, I have only scratched the surface of identity and how it relates to those living with leprosy in the Kathmandu Valley. The many institutions surrounding leprosy, including Shanti Sewa Griha, Anandaban Hospital, and Khokana Leprosarium, all impose their own view or institutional vision on those who use their services. Other groups of people such as many evangelical groups and even families of the leprosy affected all play an important role in creating dynamic and intersecting identities that are highly context dependent. Furthermore, each institution has its own view of other institutions which also contributes to this fluid continuum, and some institutions (like NGOs) do not even recognize or realize other players (like evangelical groups) that have extremely important roles (Graif 12-3-2007). The way people affected with leprosy move through these organizations at different times, or their “primary category of operation” (Graif 12-3-2007) is a fascinating topic and one I hope to explore further.

There was a man who lived in Khokana that was put into a cave by his family, but they still left food for him outside of the cave each day (Graif 12-3-2007). This is an example where a radical form of isolation is coupled with familial connection. Family members feed their family, so it is not as if the man was being completely cut off. According to Graif, this is what makes identity problematic and yet so important. Depending on the perspective, different players are imposing different views on the situation which in turn allows seemingly irreconcilable roles (like being a father who is fed by his family each day, but never being able to talk to your son) to exist simultaneously. So the leprosy colony from a governmental standpoint catches all of the people who “fall through the cracks”, while from an NGO standpoint, perhaps taking leprosy affected people in is a way to say “shame on you” to society or to instill identity as a form of empowerment onto someone traditionally viewed as “marginalized”. To the leprosy affected person, these institutions may just be a place to find shelter and food while the family of the leprosy affected person looks at these institutions as a way to ensure the family member gets fed but without having to actually do it themselves. In a way they are “fulfilling obligations via proxy” (Graif 12-3-2007). Basically I have opened the door to an attempt to deconstruct the concept of identity as mediated through a population of people living with leprosy in the Kathmandu Valley.

Conclusion

These fractured and intersecting, “hybrid” identities were present in many of the leprosy affected people I spoke to throughout my research. When addressing to what extent leprosy affected are able to assert for needs, these intersecting identities must also be taken into account. Some people asserted for needs under the international human rights organization IDEA, while others felt isolated and disabled, saying “I can’t do anything”. These types of fractured identities are not at all dysfunctional but often times allow people to act in novel ways (Graif 12-3-2007), or to reconcile irreconcilable roles in a very non-traditional way (Cramer 12-4-2007). For example, Dhag re-created social ties both inside and outside of Khokana that simultaneously existed but were traditionally at odds with one another. When the idea of hybrid identities touches the discourse on marginality, people who have gone unrecognized in mainstream society can become central agents under different circumstances. The center point is perhaps constantly shifting as different people and institution interact with one another so that in certain circumstances the NGO has more power than the “leper” but in others the leprosy affected become the sphere of influence because he or she does not self-identify as “marginalized”. It’s all very dynamic.

I believe the first step to positive development is humanizing the disease of leprosy, by listening to people’s stories and making a concerted effort to try to understand what people of a different background are going through. Personally as someone aspiring to a career in public health and medicine, an individual study

of leprosy and identity is invaluable because it has given me an entirely new perspective with which to view medicine and the work of foreign medical efforts in countries all over the world. I believe that Nussbaum asserts that development is not just about fundamentally treating a problem (as medicine tends to look at disease). By making an effort to see how people view themselves while living with a disease we can gain a much better understanding about the needs of a community (in light of their views, experiences, and critical input) and not as Ecks says, bring the “marginal” to the “center” which often creates more problems for those dealing with the disease.

Appendix A: Some Stories and Song

I spoke to brave individuals throughout the course of my research, many of whom have endured great hardships because of their associations with leprosy. They have generously shared their past with me and I would like to share some stories here. Though spacial limitations do not allow me to print all of the stores, each person I spoke to was an individual with a unique narrative. They are the reason this research is important. Here is to these incredible men and women.

Poem and Song by Mr. Raneshor Neupane: *Translated by Mina Rana (original formatting lost in translation.*

Leprosy Can Be Recovered

When I am recovered my heart is happy That is why I want to sing a few lines
Just listen all brothers the message of happiness

In 2014¹ there was a disease on my body I didn't know anything of medicine
Nothing is in life

Laughing playing during walking There was damage in hand
Up and down older people used to talk behind back

Hearts cry a lot This thing is the result of sin
This life becomes a trap what happened
Some people used to say it's curse of ancestor

Two, four years spent no medicine Hands and legs are going damaged
Can't cry sadness is raising and raising in heart a lot of hard time
Found Shantabhawan² and had medicine

Taking care of sadness of heart Had medicine around 2018
Star and moon of happiness established by Dr. Chandi

Even there wasn't a single house Tiger used to roam in jungle
Wanted to run away because heart was scared When you count whole staff
including driver there were five
Only one Dr.Chandi there wasn't other

This is the thing Don't need to be proud
This body doesn't lie It feels like it just happened
but in moment it is already fifty years

Men and women there were thirty-five patients Because of caste system
something was off Used to cry from time to time
They arranged only one room with low caste³ Maybe relatives find out
What to do?

My stomach moves because the gross woman cobbler touched food
How to eat food touched by cobbler woman? It is better to die at home
Want to be discharged

Among them some died, some left According to time people have these feelings
There was rich and poor and there was a lot of caste system conflict
Why not There wasn't any education Why shouldn't it be damaged?

Time came and passed How is it, these things like a dream how time moved
Hills surrounding whole houses Now what is the bad thing?

That time and this time let's compare Where did nature arrive draw in your heart

¹ The year 2014 on the Nepali calendar corresponds to the year 1957 on the Roman calendar.

² Shantabhawan is the original name for Anandaban Hospital

³ Reference to Dalit caste

By eating by moving having fun you won't know anything If remember the hard times now this heart doesn't cry

Who takes rocket in the sky doesn't worry if globe falls down Too much factory of education Because of that the water source will dry up

There is help for big and small No worries

Medical camps go east to west

If there is serious patient they bring in hospital They help children go to school

Everyone helps thanks for doctor from my side

Because of help recovered Thank you because I am alive

From very little I almost died because of disease What happened?

Being alive, being poor people don't have a choice to live or die That is why even though poor can't say I'll die

If I said??? It could be big The whole worlds clouds will cry

Many things happen in life If I did wrong I am sorry

Yam: *Conversation translated by Pratima of Shanti Sewa Griha*

Yam is a 72 year old man from Palpa in Western Nepal. He got leprosy 35 years ago and has been living in Shanti for 10 years. He says that without Shanti he can't survive because he gets much help and shelter from Shanti. At first, he knew nothing of leprosy so he did a traditional puja. Later he took medicines. He bought some medications and got some free from the hospital. Nobody taught him how to properly take the medications. He didn't take them every day and now his fingers are gone.

He left his family 19 years ago to come to Kathmandu. He has one son and a wife but they both hate him. He has had a very difficult time. Sometimes he begged on the streets for his meals. He struggled from place to place working for enough food. He went back and forth between Teku and Patan hospitals until Dr.Hiraman put him into Sewa Kendra.

He hasn't been back to his village for 45 years. "To survive in the village is difficult", he says. For Dassain and Tihar he went to the Kali temple. He also did Tikka for everyone at Shanti on Dassain. People at Shanti think of him as their grandfather or father. "The people here aren't only friends", he says "Here at Shanti we are like a family".

He has no feet. "I can't do anything", he says. Sometimes he feels like leprosy is nothing and just a small disease because his insides are healthy. Sometimes he feels like leprosy is a very strong and hard disease. He can not do strong work. "I am poor and sad".

He wants to stay with his family but can't because they don't want him and the environment is not good for his health. He can't get medications in his village. "I had leprosy so I had to struggle", he says. "Nobody helps leprosy people. Even educated people hate leprosy people. Foreigners come and help us. So why our own country didn't help?" He wants to tell others "Don't hate. We also need some love because we are also human beings".

Mina: *Conversation translated by Pratima of Shanti Sewa Griha*

Mina is a 68 year old woman from Godavri. She has had leprosy since she was 13 years old and has lived in Shanti for 8 years. She has a husband, her husband's second wife, and one son. When she got leprosy her husband remarried. Her husband hated her. "He didn't want to stay with me", she says. Two years later she started getting ulcers and has bad fingers. After her husband remarried she moved in with her in-laws and he moved out. She still has contact with her son. When she visits him they eat together with the same thali. In the last year she has seen her son four or five times.

Before she got old, she used to work in agriculture. Her son got married and her daughter-in-law didn't like her so she got in contact with a friend and came to Shanti. At Shanti she does office and cleaning work. She says she likes Shanti, "without Shanti maybe I would be dead". She makes 1500 rupees per month. It is a bit less than she needs, as she must purchase bus fare, clothes, and shoes. Food is provided at Shanti. She says that compared to a normal person, outside of Shanti she can not do very much but inside Shanti she can do some things "even compared to a normal person".

I asked her to describe herself. Her response was that she has to struggle, her husband has a new life, and she came to Shanti. "How am I to identify myself?" she says. She continues to say that leprosy is not only a disease --"God gives this disease".

She begins to cry and says that talking of the past makes her sad. "We want to stay with our own family". "I want to stay with my son and daughter-in-law". But she can't.

Janaklal: *Conversation conducted in Hindi and translated by Mina Rana at Anandaban Leprosy Hospital*

Janaklal is a 60 year old man from Matiyari in India near the border of Nepal. He has a wife, two sons, and two daughters-in-law. In 1992 he went to Biratnagar Hospital where they subsequently sent him to Anandaban. He has currently been in Anandaban for three months but will return to his village after completing treatment. About two months ago, he had his right leg amputated here and is still having trouble with his right leg.

“People in the village hate a lot”, he says. They treat him badly and will not come close to him. He can not work because of his legs, but before he was a farmer. He would prefer to go back to his village than to stay in Kathmandu, but he needs more treatment so he would like to just stay in the hospital until it is finished. Anandaban has told him to come back in a few months but it costs 10,000 rupees to travel and he doesn’t have much money.

In reference to his home life he says “If they do bad to me, where can I go?” and it seems he feels like a burden on his family. He says that leprosy is attached with life. “If you don’t have legs, if you don’t have hands, what can you do?” Other people say, “He has leprosy. It is his luck”. He just keeps quiet. He doesn’t care what others say.

Vishnu Maya and Bhairab Bahadur: *Conversation translated by Mina Rana at Khokana Leprosarium.*

They met 40 years ago and married here. They have one daughter in Baneshwor. Vishnu is from Bhaktapur and Bhairab from Pharping.

She was 9 years old when she found out about the disease. She did treatment but her fingers were numb and senseless. She always used her hands to hold hot things and now she has no fingers.

He doesn’t have his “own family” because he was 10 years old when he came to Khokana. His father also had leprosy and had been at Khokana for 55 years. He used to work in the fields and didn’t realize the friction on his shoes. He had to have an operation one year ago because ulcers formed on his feet.

She was 18 years old when she came. Here in Khokana it is a tradition to get people married. In her family there are 3 brothers who are very nice to her. 12-15 years ago when she could still walk she would visit them. Sometimes her brothers visit her in Khokana.

He knows all about leprosy, and proceeds to name the medications and explain how he “takes a smear from time to time to test for bacteria”. He helps take care of others in Khokana because he is able-bodied. Sometimes he will change dressings of those who can’t make it to the clinic. He doesn’t know about discrimination surrounding leprosy because he has been here all his life.

Dilip: *Conversation translated by Mr. Chiranjivi Sharma at Patan Hospital*

Dip is a 29 year old Dalit man from Jhumla. In the beginning he didn’t know he was affected by leprosy. He lived 6 months to a year without medication—not realizing. There is no special treatment available in Jhumla. By the time he started taking medication his hands began to claw and his skin color changed.

His skin problem caused his community to shun him. The Maoists tried to support him by forcing him to marry and “take her son” seven hers ago. For treatment the Maoists gave him 15,000 rupees and helped him come to Nepalganj. He went to India for treatment and when the money finished came back to Nepalganj. He began asking for donations. He had nowhere to sleep and nowhere to go.

His wife told him to go away and live in a cow shed. About four years ago he went to the airport and the army arrested him thinking that he was a Maoist. But they saw he was sick and brought him to Bir Hospital in Kathmandu. He stayed there 14 days and was then referred to Anandaban where he lived for two years. This whole time he had no contact with his family. Now he is living in a rented room at the Kopan rehabilitation center. He makes 1200 rupees per month in a paper factory. “Here there is no stigma”, he says.

In the last four years he has gone back to his village once for 3 days. He stayed with his family for one day and then left because they started to look at his hands and feet and avoid him. He wants to go back but it is very hard and his wife is still not accepting him.

He is also worried to go back to Jhumla because of his former Maoist involvement. He has land and some things in Jhumla but he is afraid the Maoists will prevent him from getting it back. His land is in his wife’s name and he is afraid to loose it. He wants Mr. Sharma and Mr. Sharma’s father-in-law to mediate with the Maoists for him.

He converted to Christianity when he was in Anandaban. He started reading the bible. The resurrection of Christ was a miraculous event. Jesus healed leprosy affected, the blind, and others. This impacted him and he thinks since Christianity his problems have been less.

After returning from Jhumla he could not walk at all. Mr. Sharma’s mother-in-law, a pastor, came to his room and prayed for him. The next day he could walk. He was so excited that he went to Church. He asks Mr. Sharma to pray for his problems.

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