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## Self-Mortification and the Stigma of Leprosy in Northern India

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*This article examines the biocultural dynamics of social discrimination and physical disfigurement among people with leprosy, or Hansen's disease (HD), in Banaras, northern India. Based on the narratives and observations of people living in colony and street settings, I trace three destructive processes by which the social stigmata of leprosy become physically expressed. First, strategies of concealment further the progression and spread of HD through late detection and undertreatment. Second, the internalization of stigma can lead to bodily dissociation and injury through self-neglect. Finally, some people intentionally seek injuries under conditions of desperate poverty. As a result of such mortification processes, these people came to embody, quite literally, the prejudices that exacerbated their condition in the first place. [leprosy, stigma, disability, India]*

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The burden is worse than the bacteria. You see, the infection is easily treated, easily cured with [multidrug therapy]. . . . But even when the leprosy has been totally eliminated, many people will treat you as someone who is cursed for all time. That is the major problem.

The statement above was made by Ramchandra, a middle-aged Banarsi man interviewed as part of 22-month ethnographic study of social discrimination among people with Hansen's disease (HD, a.k.a. leprosy) in northern India. Ramchandra's statement echoed a common assertion among Indian HD workers that the social stigma of leprosy is far worse than the disease itself. Contrary to many popular beliefs, HD is a mildly contagious condition that can be readily treated with antibiotics in most cases (Bryceson and Pfalzgraff 1990). In the minority of more prolonged and difficult cases, simple precautions and careful observation are all that are needed to prevent the onset of permanent disabilities (Srinivasan 1994). In contrast to these clinical realities, however, Indians with HD are often permanently ascribed to the most untouchable categories of humanity (Frist 2000). Moreover, this untouchability often persists long after they have been "cured" of the disease, creating lifelong prospects of divorce, eviction, loss of employment, and ostracism from family and social networks (Kopparty, Karup, and Sivaram 1995).

The extreme discrepancies between the clinical and social realities of HD in India underscore a common distinction in medical anthropology between the

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pathophysiology of disease and the human experience of illness as suffering (Kleinman 1988).<sup>1</sup> As such, it is tempting to segregate the bacteria of Hansen's disease from the social burden of leprosy. Yet, although this distinction may be useful for initial criticism, further examination reveals that, like many other discredited medical conditions, the physical and social stigmata of HD are too interconnected to be adequately disentangled. As such, leprosy is best approached as an illness of discrimination *inclusive* of its physical condition.

In this article, I examine the biocultural dynamics of social discrimination and physical disfigurement among people with HD in the Varanasi district of Uttar Pradesh, northern India. Drawing on the illness narratives and observations of people living in colony and street settings, I trace three destructive processes by which their social stigmata became physically expressed: (1) concealment leading to undertreatment; (2) dissociation and self-neglect; and (3) self-mutilation under conditions of extreme poverty. These processes represent self-mortification in every sense of the word—shaming, necrosis, and the subjection of the flesh by discipline or denial. As such, these people came to embody, quite literally, the local prejudices that exacerbated their condition in the first place. Although deeply experienced by a few, the marks of leprosy are situated in a perpetuating cycle that extends well beyond the patient communities themselves.

### The Bacteria and the Burden

There is both a sharp contrast and intimate connection between the clinical and social realities of leprosy in India. *Mycobacterium leprae* is among the least contagious of human pathogens. It is estimated that the bacterium produces symptoms in less than 10 percent of the human population, and only then after prolonged exposure and a five-year incubation period (Bryceson and Pfalzgraff 1990). Although evidence suggests a hereditary component to this susceptibility, in most cases spouses and children of those infected never contract the disease (Mira et al. 2004; Seghal 1994). *M. leprae* fares even worse outside its human hosts. Indeed, it grows so poorly under most conditions, natural or artificial, that its exact mode of transmission has yet to be proven (Sasaki et al. 2001).<sup>2</sup>

In contrast to the bacterium, the social mark of leprosy in India is highly contagious. Consistent with Goffman's so-called courtesy stigma (1963), friends and relatives of people with HD 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 (Kopparty, Karup, and Sivaram 1995). With very poor chances of employment and little, if any, support from home, these exiles have few options for survival. Typically, they must find subsidized living in an isolated colony or else live on the streets and beg in areas frequented by tourists and pilgrims. Both of these subsistence modes contribute, in turn, to the stereotypes from which their discrimination originated.

Among those susceptible to *M. leprae* infection, the disease is usually treatable with a combination of three antibiotics, commonly referred to as multi-drug therapy (MDT). In most cases, this regimen can render a patient noninfectious in 30 days, and noninfected in six to nine months (Ponnighaus 1995).<sup>3</sup> Yet, for people like Ramchandra, the social stigma of leprosy can last a lifetime, regardless of whether

they have been biomedically cured of the disease. I followed 72 such cases in three groups over periods ranging from two to four years.<sup>4</sup> Although a few were able to mitigate their untouchability in urban public spaces, no one had gone so far as to permanently reunite with their original households during that time. Later in this article, I present case studies that demonstrate how the intense and intractable nature of this social burden contributes to the spread of the bacteria through the avoidance of leprosy treatment workers and clinics.

Some of the most prevalent myths about HD concern its associated deformities and disabilities. Contrary to many popular beliefs, HD does not cause limbs to rot off. Although a small percentage of cases experience internal loss of cartilage and bone at the face and digits, the vast majority of physical deformities result from accumulated trauma. Typically, the selective infection of peripheral nerves results in limb anesthesia, diminishing people's ability to rely on touch and pain to prevent injuries to their hands and feet and to make the constant micro-adjustments necessary to prevent pressure ulcers. The resultant injuries and ulcers accumulate, and along with secondary infections, lead to progressive amputations not unlike those found among people with diabetes (Brand and Yancey 1997; Bryceson and Pfalzgraff 1990; Jopling 1988).

Even in cases of permanent neuropathy, physical deformities and disabilities can be prevented through basic measures like custom footwear and training in injury prevention. But that which is basic is not always easy. Because of the ever-present threat of injury to anesthetic limbs, people with HD neuropathies must be hyperaware of their bodies in relation to their surrounding environments (Brand and Yancey 1997). Without constant visual inspection of an insensate hand, a cigarette or hot stove could result in a third-degree burn in less than a minute. More insidiously, without regular attention to footwear, or scheduled readjustments while sleeping, a pressure ulcer could work its way to the bone in a manner of weeks. Although straightforward, such preventative measures are challenging to maintain under the best of conditions. They become formidable under the conditions of extreme poverty and demoralization that is common among people who are publicly branded as "lepers" in India.<sup>5</sup> The social and physical disabilities of HD are not only mutually engendering, but they actually impede efforts to prevent one another.

### **Leprosy on the Ganga**

Banaras (a.k.a. Varanasi, or Kashi) is one of the oldest and largest centers of pilgrimage in India, revered by Hindus, Muslims, Buddhists, and Jains, who come by the millions to visit its myriad temples and shrines and bathe along a three-mile stretch of *ghats* (steps) leading to the Holy Ganga (Ganges) river. Like the Ganga itself, the sanctity of Banaras is closely linked to its capacity for absorbing the ritual pollution and sins of any and all who reside within its sacred spaces (Barrett 2002). Its many pilgrims bring a steady flow of donations, and the city's numerous ashrams, settlements, and squatter camps are ready possibilities for transient living. As such, Banaras is a major destination for a variety of indigent and socially discredited populations, people with HD among them.

Part of my ethnographic fieldwork focused on the lives and illness narratives of two HD-diagnosed communities in the greater Banaras area: the long-term

residents of a leprosy treatment facility within an isolated religious retreat, or ashram; and an indigent squatter community beside the river. These two communities represented only a small subset of the nearly half million registered cases in India at the time of my research (WHO 2000), many of whom would not have been discredited because they were treated without ever being publicly identified. Yet these marginalized groups are especially relevant in that they have come to characterize the most common stereotypes of people with leprosy whom everyone seeks to avoid: the colony resident and the street-dwelling beggar.

The treatment center of the Kusht Seva Ashram (KSA) is situated in a village-cum-truck stop just across the river from Banaras. The KSA clinic is one of the most popular leprosy treatment centers in northern India, visited by thousands of patients every year. It is sponsored by a heterodox religious sect known as the Aghori, and staffed by Ayurvedic physicians who provide free services and low-cost herbal medicines that are manufactured in the ashram. Although it mainly serves an outpatient population, KSA has separate facilities for up to 40 residential patients.

When I conducted interviews at KSA in the late winter of 1999, 31 HD-diagnosed adults (26 males, 5 females) resided within the walls of the ashram. Although all were ostensibly inpatients, their average length of stay was 5.2 years, with nearly a third residing longer than their recommended three years of treatment. These extended stays had more to do with social than medical needs, such that the KSA effectively functioned as a religiously sanctioned leprosy colony.

The second community consisted of outpatients served by an NGO-sponsored street clinic. Through clinic contacts, I interviewed 17 of approximately 25 people who were then living in squatter camps around Dashashvamedha Ghat, the area beside the river frequented by the majority of pilgrims when they first arrive in the city. Although all of these people had been cured of the *M. leprae* infection, residual deformities marked them as *korhia* (lepers) for life.<sup>6</sup>

The indigent community of Dashashvamedha made their living off the alms of pilgrims, who would drop small coins and handfuls of rice into outstretched hands and waiting bowls in order to cast off a bit of sin before bathing in the Ganga. As such, begging provided a service not unlike that of the many ritual specialists in this area, who took on the karma of others in exchange for basic resources (see Parry 1986; Raheja 1988). For this reason, I have argued that they are the true Mahabrahmins of the ghats (Barrett 2002). Yet, unlike the many high status pandits and priests of Banaras, the absolving role of its beggars only reinforced their social and economic poverty.

The KSA and Dashashvamedha groups were mainly comprised of people from Bhojpuri-speaking rural areas of eastern Uttar Pradesh and western Bihar. Most were tenant farmers, unskilled laborers, and housewives from poor and landless families, a situation consistent with the long-time association of leprosy and poverty in India (Buckingham 2002). All but one identified with a Hindu religious tradition.

The significant demographic differences between the Dashashvamedha and KSA populations occurred along the lines of gender and education. The 2:1 ratio of men to women in Dashashvamedha was consistent with the sex distribution of HD in India (Kumar et al. 2001; Noordeen 1994), an ongoing puzzle that may well be explained by the diminished autonomy of women with respect to medical

**Table 1**  
**Kusht Seva Ashram (KSA) and Dashashvamedha (DAS) individuals by years of formal education ( $X^2 = 5.42$ ;  $DF = 1$ ).**

Education	0	1	2	3	4	5	6	7	8	9	10	11	12	Total
KSA	19	0	1	0	0	2	1	1	1	1	2	2	1	31
DAS	16	0	0	0	0	0	0	0	0	0	0	1	0	17

decisions and access to essential health resources (Beals 1976; Bloom, Wypij, and das Gupta 2001) as well as possible gender differences in manual labor practices (Barrett 1997).<sup>7</sup> With regard to the even lower representation of women at KSA, however, gender inequalities were closely linked to issues of childcare, for the ashram did not allow children to live on its grounds.

The members of the Dashashvamedha group were significantly less educated than those of the KSA (Table 1). Except for a single outlier, none of the former had even a year of formal education. The latter community had a bimodal distribution of some education and none whatsoever. Such data strongly suggest that some combination of knowledge and class had influenced the different life trajectories of these two groups in the latter stages of their illness.

Whatever combinations of gender and class may have channeled these people into colonies versus squatter camps, both shared common themes of social discrimination that exacerbated the progress of their disease at its early stages and excluded them from their home communities when their condition could no longer be concealed. The following case studies illustrate these themes and the particular ways that they physically expressed themselves.

### Disavowal and Undertreatment

Sita was an energetic and outspoken woman in her early forties who belonged to a community of goldsmiths in a small town about 70 kilometers from Banaras. She was illiterate beyond the ability to sign her own name and cynically laughed at the slim chance that she or any other woman from her community would have a formal education. She had been living at the Kusht Seva Ashram for 22 years and repeatedly spoke about the loneliness she felt from the years of separation from her natal family.

Sita was 14 when she first noticed a gray patch on her upper arm. This caused great concern in her family, because any skin blemishes or spots would have adversely affected her chances for marriage. Although she could still conceal the patch beneath her sari, there was no telling whether the condition would spread. The senior males of Sita's family decided to send her to a doctor of "English medicine," who diagnosed the HD and prescribed a course of dapsone.<sup>8</sup> She was then sequestered at home while the family hastily arranged her marriage. Her condition kept secret, Sita was married within a month and ceased taking any medications lest it be discovered.

Sita's condition remained unchanged until the birth of her first child, a daughter, four years later. She then began having numbness along her left arm and leg and contractions in her toes. Her condition no longer concealable, Sita feigned

surprise when she was diagnosed a second time. To avoid being recognized at a regional leprosy clinic, her affines accompanied her on long trips for treatment in the adjacent state of Bihar. Sita's daughter died of undisclosed causes at six months of age, and her husband died the following year. With no male children, and no one to advocate for her within the family, Sita's already marginal status declined even further. With strong pressure from her mother-in-law, Sita took up residence at KSA. To this date, both her natal and affinal families publicly maintain that she is living the pious life of a widow in an ashram somewhere in Banaras.

Sita's story illustrates the tragic consequences of denial and concealment in the progression and spread of a discredited disease. Given the social consequences, it is understandable that people would go to great lengths to conceal their condition. Unfortunately, such strategies usually result in delays between initial symptoms and diagnosis, and adherence to medication regimens (Kopparty, Karup, and Sivaram 1995; Mull et al. 1989). This problem is compounded by the segregation of HD treatment services in India (Arole et al. 2002).<sup>9</sup> Under these conditions, the most public sign of early stage HD is for someone to be seen near a leprosy treatment worker or clinic. To prevent such associations, people often travel great distances to nonlocal clinics or avoid treatment altogether (Arole et al. 2002; Dharmshaktu 1992).

The majority of HD-diagnosed people from Dashashvamedha and the KSA—59 percent and 61 percent, respectively—reported delays between initial symptoms and their first visit to a licensed professional healer. Most of these delays were described in the context of concealment strategies, as in Sita's history, or some form of denial (e.g., "I did not want to know"). Others reported that not only were they ignorant of early signs of HD, but their health providers were as well. The latter issue reflects discrimination of another sort, for the segregation of leprosy treatment services also results in a segregation of clinical knowledge.

In his reformulation of deviance as stigma, Goffman (1963) includes a taxonomy of strategies for disavowing the social mark: (1) sheltering—segregation within protective social environments; (2) passing—concealing or camouflaging the mark; and (3) covering—minimizing tensions during social interactions. Yet it is clear that these disavowal strategies provide only limited benefits to the discredited and might very well reinforce the stigma of a given condition over time (Goffman 1963; Jones, Scott, and Markus 1984). This is even more the case when the stigmatized condition is an infectious disease and the disavowal results in delayed testing or incomplete adherence to treatment (Alonzo and Reynolds 1995; Rubel and Garro 1992).<sup>10</sup>

Such dynamics forge a direct link between social stigma and the epidemiology of Hansen's disease in India. Unfortunately, however, this link has yet to be adequately measured. In accordance with World Bank guidelines, statistics for India's National Leprosy Elimination Program are based solely on the passive detection of registered cases in WHO-approved treatment centers (Ponnighaus 1995). Among such centers that I have observed in the Varanasi district, registered cases are assumed to have sought treatment elsewhere and are dropped from the books when patients fail to return after six months. Many among the KSA and Dashashvamedha had discontinued official MDT programs, and all had since sought treatment through nonofficial sources. As such, none of these people existed

in national or WHO statistics. The concealment of leprosy is not only pervasive but institutional as well.

### Dissociation and Self-Neglect

Sadness and resignation were pervasive emotions among the residents of the KSA. Laxman was no exception in this regard. At 25 years of age, he had a ninth-grade education and an acre of land, which would have made him an attractive marriage prospect in many parts of rural Bihar, were it not for contracted fingers and the wounds on his toes and feet. Ten years ago, he began having difficulty holding onto farm implements and repeatedly injured himself while working in the fields. Initially misdiagnosed, his condition worsened until he started MDT six months later. Unlike Sita, however, Laxman was never able to conceal his condition, because soon after diagnosis, his neighbors saw him being visited by a local leprosy treatment worker. It took little time for word to spread among prospective in-laws, and Laxman's family gave up trying to marry him after two aborted attempts. Laxman related these latter events as if they marked the end of his life.

Laxman continued MDT on a sporadic basis, and I suspected that he was eventually cured. Yet, although he was tolerated in his family and village, no one spoke with him and he kept to himself. In accordance with ritual pollution taboos, he ate his meals from separate pots and *thalis* (plates) and sat alone during village celebrations. Laxman stated that, "In our society, people hate anyone with this disease." He insisted, however, that the problem did not lie with his village, but rather with himself.

I was struck, not only by the content of Laxman's story, but also the manner in which he related it. Laxman kept his hands to his sides throughout most of the interview. He related his loss of manual dexterity and subsequent injuries without making a single gesture. This gesture-free narrative was repeated by nearly all of the KSA residents with whom I spoke. They kept their affected limbs beneath garments whenever possible and assumed positions and postures that minimized whatever was left exposed. It seemed that, even within the isolated confines of the ashram, disavowal persisted as a deeply ingrained habit.

In addition to these habits, the KSA residents also expressed linguistic dispossession from their affected limbs. During the course of their illness narratives, all dropped the possessive pronoun when narrating the succession of injuries to, and problems with their hands and feet. Thus, when recalling a cut or burn in regional Bhojpuri, *hamare haath* (my hand) simply became *haath* ([the] hand). In Standard Hindi, *Doctor pair ka ilaaj kya* (The doctor treated [the] foot.) instead of *mera pair* (my foot). A few even went so far as to say *yah angulii* (that finger) or *yah panjaa* (that toe) without any look or gesture toward the digit. It was as if the appendages that remained had already been amputated, or those that were amputated had left no signs of previous attachment.

These habits of word and gesture were particularly disconcerting given that many KSA residents continued to suffer from limb anesthesia, necessitating constant visual inspection and a hyperawareness of affected limbs to prevent further injuries. Although they may have been all too aware of their situation on the whole, these data indicate that the residents of KSA were actively dissociating themselves

from their physical disabilities on a moment-by-moment basis. If so, this behavior would have significant consequences for the further progression of their physical condition, even in the absence of infection.

With this background, it is interesting to note that leprologists from the U.S. Hansen's Disease Center in Carville, Louisiana, relate anecdotal observations of disdain and neglect of affected limbs among some of their patients (personal communication, Leo J. Yoder, 1998). Although situated in very different cultural contexts, many Carville patients describe themes of isolation and shame very similar to the KSA residents (Gussow 1989). While conducting life history interviews in Carville in 1997, two patients presented their narratives to me free of gestures and personal pronouns for disabled limbs (personal communication).

Murphy (1990) describes a similar process of dissociation during the progression of his paralysis and cancer. He examines the "silencing" of his body, beginning with a loss of proprioception and ending with emotional detachment. He refers to his limbs as "the arm" or "the leg," his body as a "faulty life support system," and his remaining self as "Donovan's Brain." Murphy and others examine issues of stigmatization among people with paralysis, characterizing them in terms of liminality due to lost social roles associated with sexuality and physical independence (Murphy et al. 1988). Within the same time frame, Murphy ignores parts of his own body to the point that he becomes nearly septic from bone-deep pressure ulcers (1990).

For stigmatized neurological conditions with anesthesia, the combined loss of physical sensation and social identity creates a strong potential for bodily neglect, thereby perpetuating feedback between physical pathology and the social pathology of its discrimination. Moreover, the internalization of stigma is likely to be deeper when such conditions are acquired in adulthood, given that disability prejudices are often learned early through socially ascribed prototypes of health and beauty (Ablon 1995; Jones, Scott, and Markus 1984). Thus, when confronting the physical parts by which they once identified themselves, parts that had since become misshapen and senseless, it is not surprising that some of these people would dissociate themselves from that which they have long known to be alien, and which marked their alienation from the world around them—a *disembodiment* of leprosy.

### **Poverty and Self-Mutilation**

Ram Dev insisted that I cut him. He wanted me to expand the two-inch wound on the ball of his foot with a scalpel. In biomedical terms, it was stage 4 ulcer: a crater formed by weeks of constant pressure that had gradually extended down to the bone. Because of his neuropathies, Ram Dev never felt the wound, nor would he have felt the scalpel if I agreed to his request. Yet although the healing of such wounds sometimes required the removal of dead tissue, this could usually be achieved through vigorous cleaning and a proper dressing. Such was the case for Ram Dev on this particular day, but he would have none of it.

I had been volunteering as nurse at a biweekly street clinic for people with HD near the main bathing ghat at Dashashvamedha. There, I encountered Ram Dev and several other patients who regularly sought the removal of healthy tissue and enlargement of the wounds in their hands and feet. They explained that the

additional cutting dispelled the “bad blood” that was causing their condition. Although none would admit it themselves, statements made about one another suggested that this explanatory model of bloodletting was strongly motivated by the desire to enhance physical deformities for begging. Along similar lines, a few initially resisted taking MDT on the grounds that the medicines might cause their fingers to grow back. After all, these people were marked for life, and deformities were often their primary means of survival.

The mutilation was a gradual process, one that took place in the day-to-day struggle for meager resources. People would request additional bandages. In combination with exposed deformities, the bandages would conceal something much worse in the horrors of the pilgrim’s imagination. Those with additional bandages might earn slightly more on a given day. Those with bloody bandages might do better; exposed wounds even more, the larger the better, and so on. With fierce competition for alms on the ghats, medical debridement provided a legitimate means to gain a slight advantage under the worst of circumstances. It did not happen all at once. It did not happen every day. But from time to time, some people would trade a bit of flesh for a bit more rice and money.

To fully appreciate these actions, one must understand the desperate conditions under which they occurred. The Dashashvamedha poor were crowded into makeshift shelters of loose brick covered with plastic sheets or corrugated tin. They had no access to clean water or sanitation, and were chronically undernourished. It was therefore hardly surprising that HD was the least of their medical problems. Rather, it was diseases of poverty such as tuberculosis, parasitic infections, diarrhea, and sexually transmitted diseases that presented the greatest health challenges. Among the women, the stigma of leprosy was compounded by gender inequalities and a lack of protection. Many suffered physical and sexual abuse and were forced into prostitution under the worst possible conditions. Although none of the children had ever been diagnosed, they carried the mark of their parents and spent most of their days scavenging through garbage and begging. Unfortunately, the children were exceptionally gifted at the latter, and their earning abilities often dissuaded parents from sending them to school. The social mark of leprosy was not only physically harmful, but heritable as well.

In addition to these problems, heroin abuse was endemic among the adult males of Dashashvamedha, Ram Dev included. Banaras is a major retail center for heroin, and a day’s supply can be readily obtained with the earnings from a few hours of begging. It is a sad irony that people would seek pain medication for the socioeconomic consequences of a condition noted for the absence of physical sensation, but this is exactly what Ram Dev and many of his friends were doing. Pain was the chief metaphor in their illness histories, in their losses of family, friends, and social identity. Pain was also their chief somatic complaint, a generalized discomfort that was present even among those who were not seeking drugs.

The association of chronic pain with alienation and loss recurs in studies of people with discredited medical conditions, which have argued that social suffering is internalized and expressed through somatic symptoms that are indistinguishable from those of physical pathology (Good 1992; Jackson 1992; Kleinman 1992). I suggest that the same was true for Ram Dev and other drug-using members of the Dashashvamedha community. For these people, heroin was an attempt to palliate a deeply internalized suffering. It was a means to detach from the

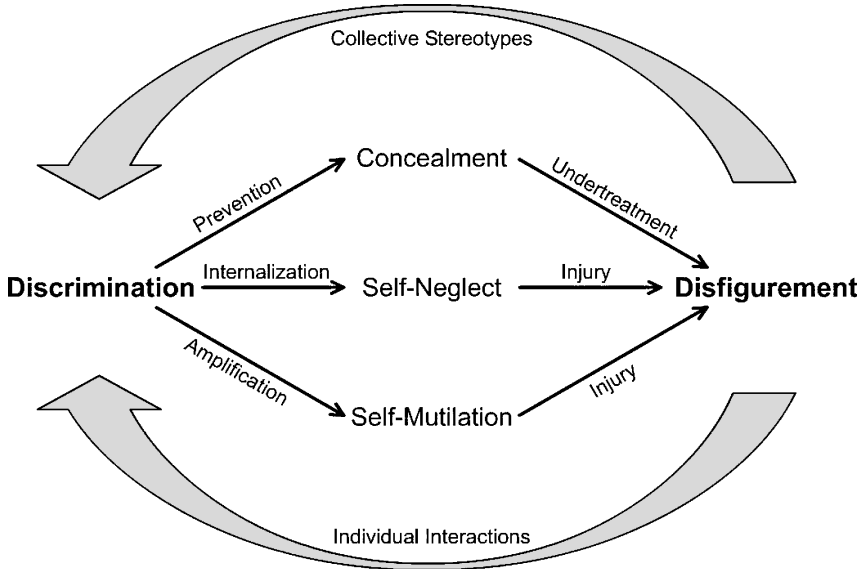
past, the poverty, and the somatic experience of self—another disembodiment of leprosy.

With this background, Ram Dev's particular method of self-mortification fits a classic picture of stigma amplification under conditions of extreme poverty and social alienation. Such amplification can be both a means of destruction and of sustenance, for it is in the interests of the discredited to maximize their out-group identity when they have no other opportunities for social integration (Becker 1963; Pfuhl and Henry 1993). Relegated to the lowest rung of humanity, the indigent community at Dashashvamedha could do no worse for their social status, and might even make slight improvements to their economic status by becoming more of what everyone expects them to be. In this manner, Ram Dev fulfilled his community expectations by becoming poor, drug addicted, and physically deformed, inscribing on to his body the very models of discrimination that put him on the streets in the first place. Waxler (1981) discusses how people "learn to become lepers [*sic*]" by being socialized into the discriminatory models around them. In the case of Ram Dev and others at Dashashvamedha, these models were not only deeply internalized. They were inscribed onto flesh per the original definition of stigma—a permanent mark, cut or burned on the skin of people so as to publicly brand them as members of a socially discredited group.

## Conclusion

The "self"-mortifications described in this article refer not to individual notions of self but rather the mutually reinforcing cycle of social discrimination and physical disfigurement that destroy people's lives (Figure 1). Strategies of concealment may further the course and spread of HD through late detection and incomplete treatment. Nevertheless, they may be the least damaging alternative, given the more severe consequences of social exposure for the lives of extended families. The threshold for neglect of insensitive limbs may be inversely related to people's aversions to those disabilities, especially when these aversions have been internalized among the patients themselves. And, finally, the deliberate pursuit of bodily mutilation is only conceivable as a short-term survival tactic when someone's life has declined beyond any other hope of change. In each of these processes, the social stigma of leprosy furthers its physical stigma, which returns to reinforce individual and collective models of discrimination.

Although not universally discredited, leprosy is the archetype of disease stigma in many parts of the world, as evidenced by the popular saying that "AIDS is the present-day leprosy."<sup>11</sup> These diseases share more than a common metaphor. HIV/AIDS persists in many countries under similar conditions of structural violence as those of HD in India, such as when economic desperation creates circumstances of pathogen exposure, or the costs of social exposure outweigh the benefits of early testing and treatment (Barrett 1995; Farmer 1992; Wojcicki and Malala 2001). Similarly, the stigma of tuberculosis and the distrust that it creates between patients and providers can impede health-seeking behaviors and adherence to the long-term drug regimens (Rubel and Garro 1992), both of which are necessary to control the spread of infection and the emergence of multi-drug resistance (Farmer 1999). For all these "leprosy," the forces of inequality (read discrimination) are more prevalent than the infections themselves. At the same time, though, such



**Figure 1**

**Diagram of biocultural dynamics between social discrimination and physical disfigurement among people with leprosy in northern India.**

forces are intimately tied to the epidemiology and pathology of their concomitant infections by constraining the individual choices that would otherwise affect their prevention and treatment.

The biocultural dynamics of stigmatized diseases strongly supports their framing as illnesses of discrimination, inclusive of their pathology, epidemiology, and both the affliction *and* infliction of human suffering that they entail. This holistic approach not only mandates active engagement between clinical and critical perspectives. It expands the scope of research beyond the locus of the marked patient, to the broader socioeconomic and historical processes from which the mark originates. As such, anthropologists are well positioned to develop a systematic framework for the understanding and prevention of socially discredited diseases.

## NOTES

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1. Kleinman's (1988) case studies illustrate that, while distinctive, illness and disease need not be exclusive categories.

2. The highest bacterial titers can be found in nasal secretions, and a number of transmission modes have been hypothesized (see Naafs et al. 2001): water (Matsuoka et al. 1999) or an anaerobic soil intermediary (Chakrabarty and Dastidar 2001). However, the model cannot be proven until the organism can be feasibly grown under laboratory conditions. To date, the only naturally infected nonhuman host for leprosy is the armadillo, an animal that does not reproduce easily under captive conditions (Bruce et al. 2000).

3. A minority of those infected are particularly susceptible to the mycobacteria. Known as lepromatous, or LL cases, these people often require a longer and more involved course of treatment over three to five years (Bryceson and Pflzgraff 1990).

4. These 72 cases resided in three different living and treatment areas: (1) Dashashvamedha (N = 17); (2) The Kusht Seva Ashram (N = 31); and (3) Asapur (N = 24). I first came to know the Dashashvamedha group in the winter of 1996–97. Although highly transient, I was able to follow up with most of them, and work with the two other groups during my main fieldwork in 1999–2000 and again during a follow-up visit in the spring of 2001.

5. Understandably, the term *leper* is considered highly derogatory by activists within the international HD community (Gussow and Tracy 1968).

6. In this part of northern India, the term *korhia* is considered so inauspicious that some people will spit after saying it, lest the word itself contaminate them. *Korhia* normally has a diacritical mark under the *r*, but the editors chose to forego diacritical marks in this article.

7. Although it is well documented that Indian women have worse access to health care resources than men, one would expect a higher proportion of physical deformities among those women who eventually obtained treatment. On the contrary, however, men have an even higher ratio (4:1) of physical deformities than women. Extending the hypotheses posed in note 2 above, and based on some preliminary observations, I suggest that the way in which men engage in manual labor subjects them to higher rates of physical trauma, and therefore, a greater frequency of high titer infections. This phenomenon is very much in need of further research.

8. Dapsone was the leading treatment for *M. leprae* infection until the early 1980s. Unfortunately, the organism began showing resistance to this sulfa drug within a decade of its introduction in 1943. Today, dapsone is considered to be merely bacteriostatic against *M. leprae*.

9. The solution of reintegrating leprosy treatment into primary care services can also be problematic. For a critical perspective, see Justice (1986).

10. See Nichter (2002) for a counter example in which health providers relabel tuberculosis within a less stigmatizing ethnomedical category in order to improve health seeking and adherence to treatment.

11. This metaphor is commonly used by Christian service organizations. See <http://www.umc.org> and <http://www.truechristianity.org> for examples.

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