

Curing leprosy amid misconceptions, stereotypes, and societal expectations

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Abstract

Leprosy is a mildly contagious disease that can be cured through a combination of antibiotic treatments. However, the clinical reality of leprosy is overshadowed by its social reality, thus worsening the lived experience of those affected. To conceptualize the severity of leprosy's social reality, this article aims to situate the disease outside of clinical boundaries by investigating the myths, attitudes, and sociocultural presumptions underlying the disease. This type of comprehensive social analysis is critical for developing regional plans to encourage clinical leprosy treatments. Therefore, studies on leprosy conducted in Bangladesh, India, Vietnam, and Nepal were taken into consideration. The review of literature that uncovered the sociocultural attitudes associated with leprosy yielded several significant insights. First, leprosy had associations with bodily pollution due to its severe physical deformities, which endangered society's ideal of purity. Second, due to the degrading connotations associated with leprosy, affected patients were abandoned without adequate economic support, forcing them to take extreme measures to survive. Finally, a leprosy diagnosis creates an insurmountable gap between their past as a healthy person and their present with leprosy, resulting in reintegration difficulties and a loss of belonging. Such negative social attitudes towards leprosy contribute to patients' reluctance to access clinical treatments in fear of social ostracism and humiliation, exacerbating an otherwise curable condition.

Keywords

Stigma, social, pollution, deformity, self-image

Introduction

Leprosy, also known as Hansen's disease, is one of the oldest infectious diseases, afflicting humanity for millennia by instilling fear and misconceptions (Santacroce et al., 2021). The disease is caused by a bacteria known as *Mycobacterium leprae*, which invades the nerve and skin and causes nerve thickening, paralysis, or severe cases of deformity (Berreman, 1984). Through the introduction of multidrug therapies and launching active case finding strategies such as contact screening and large-scale detection campaigns, mitigation of leprosy has been effective (Ballering et al., 2019). Furthermore, the emergence of permanent disabilities can be prevented by integrating simple precautions and close monitoring (Srinivasan, 1994, as cited in Barrett, 2005). Despite the global decrease in new leprosy cases, the global incidence of leprosy has remained stable over the last decade (Ballering et al., 2019). This is due, in part, to the prevalence of the social stigma associated with leprosy, which poses a serious obstacle to the disease's eradication (Berreman, 1984).

Leprosy-associated stigma delays detection, diagnosis, treatment of the disease, which in turn worsens the wellness and livelihood of the leprosy-infected people (Ballering et al., 2019). In fear of social ostracism and loss of dignity, patients refuse to disclose their condition to health-care professionals in their community (Ballering et al., 2019). Consequently, such non-disclosing attitudes obstruct early leprosy interventions, which is essential for controlling the spread of leprosy (Berreman, 1984).

Considering the detrimental impact stigma has on clinical interventions for leprosy, strategies for leprosy-stigma prevention have been at the forefront of global fight to minimize leprosy incidence. The Global Leprosy Strategy 2021 – 2030 initiated by the World Health Organization and leading public health experts from leprosy-endemic countries is one such global

effort that strives to achieve one of its three goals, ‘zero stigma and discrimination’ to end leprosy and its enduring social implications (van Brakel, 2022). Furthermore, leprosy-stigma and its influence on shaping one’s attitudes towards the disease has been of central focus in social science literature for decades – most notably, Barrett’s (2005) study of social discrimination and physical disfigurement among leprosy patients in Banaras, Northern India, and Ngoc Yen’s (2020) ethnography on Vietnamese folk constructions of leprosy, were important for asserting the social position of leprosy in this essay.

In order to contribute towards the global effort of mitigating leprosy incidence and social science research that has thoroughly investigated the implications of leprosy stigma, I aim to reinforce the point that, prior to launching initiatives to address and treat leprosy, recognizing leprosy as not only a clinical disease but also a social one is of great importance. The social aspect of the disease needs to be thoroughly investigated to appropriately structure the clinical nature of leprosy treatments. Hence, this literature will aim at contextualizing some prevalent social attitudes and assumptions about leprosy. Accordingly, the impact of leprosy stigma on clinical leprosy care will be amply demonstrated.

Background

Leprosy is an ancient infectious disease caused by bacillus, *Mycobacterium leprae* (Santacroce et al., 2021). This rod-shaped, acid-fast bacterium, surrounded by a unique and waxy cell envelope, is transmitted via droplets during close and repeated contact with untreated leprosy-infected individuals (Santacroce et al., 2021). The bacterium must be treated with multidrug therapy (MDT) regimens to prevent the onset of visible and long-lasting damage to skin, nerves, and the eyes; otherwise, they will serve as the foundation for the terrible social mark associated

with leprosy patients (Santacroce et al., 2021). Gussow & Tracy (1970) present the following quote from Honorary American Chairman, Mrs. Arthur J. Goldberg, given at the World Leprosy Day conference in 1868, which briefly, yet effectively conveys the social repercussions of leprosy stigma: “probably no other disease causes such a reaction in the community and so much distress to patients and their families” (1970: 425).

Leprosy patients were treated inhumanely by society in the Middle Ages because the disease was seen as a terrible disgrace (Santacroce et al., 2021). To further cement leprosy's low status, leprosy-infected patients were forcibly removed from their communities and placed in quarantined colonies far from cities, ensuring that the contagion was separated from the rest of the population (Santacroce et al., 2021). During this time, such undignified and fearmongering measures became widely accepted when leprosy patients were declared officially dead for the rest of society (Eichman, 1999). Their unearthly status was fully recognized after conducting a symbolic funeral service to assert that they are no longer the individuals they once were, but rather embody a state of grossness and fear that must be avoided (Eichman, 1999). The leprosy patients were further humiliated by being forced to wear a mask and garments to conceal their disfigurement, as well as carry a bell to warn others of their arrival (Eichman, 1999). While these actions were both insulting and cruel, they did help to reduce the spread of leprosy throughout Medieval Europe (Eichman, 1999).

Despite modern-day advances in understanding of bacterium behavior and disease transmission, societal perceptions of leprosy remain unchanged. With the development of leprosy stigmatization theory, considerable efforts have been implemented to change the name of the disease to Hansen’s disease or “so-called leprosy” to illuminate the present reality of leprosy and stray away from misconceptions and myths of the past (Gussow & Tracy, 1970). The theory also

aims to emphasize that the negative connotations of leprosy are exaggerated and unrelated to medical and physiological facts (Gussow & Tracy, 1970). Nonetheless, isolation and confinement of leprosy patients in leprosaria and leper colonies continues to be practiced all over the world (Gussow & Tracy, 1971). The belief that leprosy patients must be separated creates stigma for both the infected individual and the disease, which is difficult to overcome even after the disease has been cured (Gussow & Tracy, 1971). The persistence stigma and experience of discrimination will coerce leprosy patients to isolate themselves from society (Jose & Suresh, 2021). This overwhelming social experience of leprosy patients becomes a barrier to proper medical care and reintegration into their communities (Jose & Suresh, 2021). Hence, it is clear that stigmatization of leprosy patients will persist as long as poor understanding of disease etiologies, ignorance, and superstition are prevalent (Jose & Suresh, 2021).

Leprosy – the polluter and threat to social purity

Leprosy is a serious threat to communities that centralizes the dichotomy between cleanliness and contamination. This is clearly depicted in the context of Vietnam's Qui Hòa leprosy village, who views leprosy bodies to be indistinguishable from dead bodies (Ngoc Yen, 2020). According to the Qui Hòa villagers, dead bodies are in the process of decomposing, they are neither human nor alive but still have not vanished from the physical world (Ngoc Yen, 2020). Instead, they are situated in a liminal period prior to their decomposition (Ngoc Yen, 2020). Leprosy patients, on the other hand, are alive but have body parts that appear 'decayed' and 'eaten' (Ngoc Yen, 2020). Due to leprosy bodies uncanny resemblance to dead bodies, leprosy patients' very existence is considered polluting (Ngoc Yen, 2020).

Even in South Asia, especially in Bangladesh, India, and Nepal, there are firmly held beliefs about purity and pollution (Barrett, 2005; Hyland, 2001; Wilson-Moore, 1995). In order to distinguish one caste from another and organize the basic structure of society, purity and pollution are crucial elements (Shah, 2007). However, pollution, in particular, is feared because it can contaminate anyone in close physical or familial proximity (Wilson-Moore, 1995). Therefore, those who are viewed as polluting and impure are reduced to insignificant members in society (Shah, 2007). Given the disparity between purity and pollution, being afflicted with leprosy is a daunting experience because it is not only biologically contagious, but it is also ritually polluting (Wilson-Moore, 1995). The ritual pollution caused by leprosy is of particular concern because it jeopardizes the symbolic purity and honor of families and communities (Wilson-Moore, 1995). Hence, in fear of being associated with pollution, leprosy patients often conceal their symptoms by being covert of their condition or travel to clinics far from their hometown to receive necessary clinical treatments (Barrett, 2005). Otherwise, leprosy patients risk being shunned by their family and community (Barrett, 2005).

To fully investigate the impact of associating leprosy with pollution, the treatment-seeking behaviors of leprosy-infected South Asian women must be highlighted. Even though both South Asian men and women are imprinted with ideas of purity and impurity from birth to death (Shah, 2007), South Asian women most often than not bear the brunt of the burden. Given this, in Bangladesh, India, and Nepal, women with leprosy frequently conceal their damaged skin with garments or refuse to see a doctor soon after noticing symptoms (Barrett, 2005; Hyland, 2001; Wilson-Moore, 1995). By concealing their disease, they risk inflicting severe and long-lasting damage to their physical health (Barrett, 2005). Nevertheless, South Asian women are adamant about hiding their illness despite the gravity of their behavior. If their community learns of their

illness, they run the risk of being associated with pollution, which can lead their family and community to alienate them (Wilson-Moore, 1995). Since preserving and restoring purity is of utmost importance in South Asian culture, particularly for the Hindu community (Hyland, 2001), the 'impure' one needed to be excluded from the community. Therefore, considering the social ramifications of being labelled as 'impure' or 'polluted,' it was deemed necessary for women to conceal their leprosy (Hyland, 2001).

The unrecoverable past and difficulties with reintegration

Gussow & Tracy (1968) asserts that leprosy can alter the due course of one's life. Leprosy creates boundaries and obstacles that drastically undermine a patient's pre-leprosy social identity (Gussow & Tracy, 1968). The diagnosis of leprosy signals an unexpected, severe, and unwelcome change in the patient's life (Gussow & Tracy, 1968). Due to the severity of the disease and the need for ongoing treatments to keep the symptoms under control, patients are expected to modify, or in the worst case, abandon relationships or activities they had engaged in prior to contracting leprosy (Gussow & Tracy, 1968). Due to the discontinuity between the past and present, as well as the dissonance between their self-identity and their social identity, many chose to conceal their condition while engaging in their pre-leprosy life (Gussow & Tracy, 1968). Even though patients are aware that they cannot retain their pre-leprosy identities, they must demonstrate to their circle that they have not changed by adopting new roles, routines, and attitudes to conceal leprosy traces (Gussow & Tracy, 1968). However, if their condition is discovered, patients are tasked with creating a new world in which they must decide what from the past must be abandoned and what relationships and social identities can be recovered (Gussow & Tracy, 1968).

This ‘new world’ that leprosy patients have created is not of their own making; rather, it is the result of them accepting and internalizing the stigma and myths surrounding their condition (Jose & Suresh, 2021). Even after leprosy has been cured, the patient cannot regain their pre-leprosy identity because society (i.e., their family and community) forever associates them with the disease (Jose & Suresh, 2021). A leprosy study conducted in India demonstrated that patients who had been cured of the disease were still faced with hostility from their family and community, making it difficult for them to reintegrate into their lives prior to contracting leprosy (Jose & Suresh, 2021). Even after being cured, leprosy patients have to sever family ties and forge new ones in a community where they are accepted because families are reluctant to accept their new identity (Jose & Suresh, 2021). These communities are typically housed in hospitals, ashrams, mandirs, and leprosy sanatoriums (Jose & Suresh, 2021). One such community is the Quy Hòa village in Vietnam, where leprosy patients are treated and monitored with great care by the medical staff (Le, 2016). These communities are critical because they provide a safe haven for patients who have been through a traumatic process of exile, degradation, and withdrawal (Le, 2016).

Despite the positive outcomes of establishing leprosy treatment communities, isolating leprosy patients from the rest of society should not be encouraged or normalized. By separating leprosy patients from their families and communities, we are asserting that people who have the disease are completely different beings who pose a threat to the established social order. Furthermore, given the social stigma associated with leprosy, finding communities where leprosy patients' new identities are accepted is challenging and causes a great deal of psychological distress (Jose & Suresh, 2021). Therefore, rather than enduring the struggles of assimilating into their new identity, as mentioned earlier by Gussow and Tracy (1968), leprosy patients would conceal their disease symptoms to retain their pre-leprosy identity.

Internalizing the leprosy monsters as means of survival

Leprosy is one of the most stigmatized diseases because it causes horrifying morphological deformities to the body (Jose & Suresh, 2021). The name 'leprosy' itself elicits the image of a ravaged and untreated victim (Gussow & Tracy, 1968). Since the deformed bodies of leprosy patients are imagined to be horribly disturbing, the connotations associated with the disease are deeply degrading, signifying a reduced personhood (Gussow & Tracy, 1968; Ngoc Yen, 2020). The belief that leprosy causes victims' toes, ears, noses, and other appendages to fall off adds to the fear associated with the disease (Ngoc Yen, 2020).

As a consequence, themes of ambiguity and hybridity are often intertwined with the perception of leprosy, which contorts the image of leprosy-infected patients (Ngoc Yen, 2020). For instance, in Vietnam, Leprosy patients' faces have been compared to lions' faces in instances where the condition causes a collapsed nose (Ngoc Yen, 2020). Due to the fact that many leprosy patients have severe eye muscle issues that prevent them from even closing their eyes while sleeping, this has prompted comparisons to rabbits, who are thought to sleep with their eyes open (Ngoc Yen, 2020). Additionally, leprosy patients' hands were often compared to monkey paws due to the loss of hand muscles between the thumb and index finger (Ngoc Yen, 2020). Such grotesque connotations instill unnecessary fear in leprosy patients, perpetuating the disease's stigma and undermining one's self-esteem.

Due to the degrading stereotypes associated with the disease, leprosy patients are forced to endure social rejection, which prevents them from receiving the essential socioeconomic support and assistance (Kaur & Van Brakel, 2002). As a result, leprosy patients are forced to undertake drastic measures in order to survive (Barrett, 2005). Some leprosy patients have chosen to

internalize the demeaning connotations associated with their disease to make a living, as demonstrated by Barrett's (2005) study of leprosy in Northern India. In Northern India, leprosy-infected individuals would choose to worsen their condition through self-mutilation (Barrett, 2005). This procedure involved the use of sharp objects to remove healthy tissues and enlarge their wounds (Barrett, 2005). They justified self-mutilation on the grounds of dispelling the 'bad blood' that was causing their condition, yet in reality, they wanted to worsen their physical deformities for begging (Barrett, 2005). They even refused to take multidrug therapy in fear of curing their leprosy-caused deformities, which were their primary means of survival (Barrett, 2005). This is not an isolated case, as shown in Wilson-Moore's (1995) study, in which some Bangladeshi people with leprosy turn to begging to as a means of subsistence.

The leprosy patients' refusal to receive adequate clinical care and use of their physical disfigurements as a source of income shows that they are aware that the degrading stereotypes that the disease and they bear are permanent. Even after they are cured, their communities will continue to regard them as unearthly hybrid beings or monsters who should be kept out of their social order. Since the severe physical disfigurements jeopardizes leprosy patients' chances of employment (Jose & Suresh, 2021), and their physical existence is assumed to be repulsive to receive community support (Kaur & Van Brakel, 2002), some are forced to worsen their skin lesions in order to internalize the monster that society wants them to be. Subsequently, the same condition which demonizes their existence becomes their only source of income.

Solutions to combating leprosy stigma

The previously mentioned negative sociocultural attitudes and stigma associated with leprosy must be addressed because they force patients to conceal their illness, causing treatment

to be delayed and the disease to spread throughout the community (Ogban et al., 2020). However, given the scarcity of literature on the subject, reducing leprosy stigma and encouraging people to seek clinical leprosy care is a challenging endeavor. Furthermore, because the underlying root causes of leprosy stigma vary across contexts, there is no single definitive solution to eliminate or reduce the social ramifications of it. Nonetheless, we should not simply give up because by examining the critical steps taken by several countries with resurgent leprosy cases, we can determine how to end stigma and discrimination and promote inclusion.

For example, consider Bangladesh, being one of the global priority countries for leprosy, the nation has implemented several actionable measures to reduce leprosy stigma (World Health Organization, 2018).

1. Revoked the Lepers Act (1898) to eliminate laws that permit discrimination of persons affected by leprosy.
2. Providing IEC materials that dispel leprosy myths and misconceptions and involving primary social actors such as religious leaders to initiate innovative activities for stigma reduction.

India is also at the forefront of leading initiatives to combat leprosy stigma given that 3% of the persons affected by leprosy experience self-stigma (World Health Organization, 2018). To improve community participation, India has integrated leprosy services into general health care and carried out Sparsh leprosy awareness campaigns (World Health Organization, 2018).

Bangladesh and India's initiatives reveals that increased community participation, systematic changes, and expanding one's knowledge about leprosy are critical for combating leprosy-related stigma. These initiatives are still broad, but they are the foundation for focusing on

localized strategies to reveal the clinical reality of leprosy, which is that it is a curable condition when treated appropriately.

Conclusion

To summarize, leprosy as a polluting disease that crosses moral, social, and cultural lines portrays leprosy-infected people as menacing figures who clash with the sacred elements of purity. Furthermore, associations with grotesque images and a loss of normalcy after a leprosy diagnosis exacerbate patients' perceptions of their disease. Misconceptions about leprosy, in conjunction with self-stigmatization, justify leprosy patients' marginalization from the community and discriminatory behavior towards them, worsening the patients' lived experience. As a result, patients frequently choose to conceal their disease symptoms and avoid seeking treatment in order to maintain their honor and dignity, which ultimately worsens an easily treatable condition. Although never simple, local initiatives must be put in place to recognize leprosy stigma and address them accordingly. In essence, leprosy is an infectious global disease that must be addressed locally.

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