

Review Article

Review Article on Beliefs and Myths on Leprosy

Uzma eram¹, Deoshree akhouri², Shazia Parveen³

¹Assistant professor in the Department of Community Medicine, J.N.M.C.H, A.M.U., Aligarh, India

²Assistant professor in the Department of Psychiatry, J.N.M.C.H, A.M.U., Aligarh, India

³Assistant professor in the Department of Obstetrics and Gynaecology, J.N.M.C.H, A.M.U., Aligarh, India

*Corresponding Author:

Uzma eram

Email: uzmazoya27@gmail.com

Abstract: Leprosy is also called as ‘numbing skin disease’ or ‘Hansen’s disease’. The stigma attached to leprosy persists in many countries. At an early stage, leprosy may manifest itself only in mild skin lesions, but if left untreated, these lesions can become much more noticeable. Some people with leprosy may have a distinctive odour caused by infected ulcers. Since ancient times, leprosy has been interpreted as God’s punishment of the sinful. Other causes of leprosy which people have been reported to traditionally believe are witchcraft, a curse, trespassing of food taboos, contagion, and being hereditary. Leprosy is more a social problem rather than just a medical disease. A review of the literature showed that the stigma, misconceptions and negative attitudes towards leprosy patients are prevalent in most communities. Most misconceptions pertaining to leprosy, in particular the beliefs in heredity, evil spirits and contact with prostitutes as causes of leprosy, were found to be most common. In addition, deformities arising as a consequence of untreated leprosy played a significant part in increasing the stigma to leprosy. Health providers should also learn problem-solving skills to assess the patients’ reasons for defaulting treatment or follow-up and act on them. This means that they should be trained on techniques to analyse and motivate behaviour change.

Keywords: leprosy, myths, beliefs, review article

INTRODUCTION

Leprosy is also called as ‘numbing skin disease’ or ‘Hansen’s disease’ [1, 2]. The stigma attached to leprosy persists in many countries [3-6]. At an early stage, leprosy may manifest itself only in mild skin lesions, but if left untreated, these lesions can become much more noticeable. Some people with leprosy may have a distinctive odour caused by infected ulcers. This smell can be nauseating and was made worse in cases in which their communities did not allow people with leprosy to wash in communal water, as described in a report from Madhya Pradesh, India [7]. Since ancient times, leprosy has been interpreted as God’s punishment of the sinful [8-13]. Other causes of leprosy which people have been reported to traditionally believe are witchcraft, a curse, trespassing of food taboos, contagion, and being hereditary [14, 15]. Leprosy is more a social problem rather than just a medical disease [27, 28].

REVIEW OF LITERATURE

Early texts, e.g. the Atharava Veda (circa 2000 BC) and the Laws of Manu (1500 BC), mention various skin diseases translated as leprosy. The Laws prohibited contact with those affected by leprosy and punished those who married into their families [16]. The Sushruta Samhita (600 BC) recommended treating leprosy—or

kushtha, meaning “eating away” in Sanskrit—with oil derived from the chaulmoogra tree; this remained a mainstay of treatment until the introduction of sulfones [17].

Social constructions of leprosy are commonly guided by cultural, traditional and religious beliefs or myths about disease and illness [18,19] in India [20] and many African countries [22]. Too often, leprosy infected people are thought of as cursed or victims of witchcraft, or as blameworthy / immoral; and their disease well deserved [21].

People with leprosy may be refused employment or lose their jobs because of their disease [23]. For example, in an Indian study by Prabhakara *et al* [24], they found that 16 – 44% of leprosy patients experienced a fall in their income. Furthermore, in a South African study of the psychosocial needs of leprosy patients, Scott [25] found that the subjects all feared losing their jobs and 17 out of 30 concealed their disease from their employers.

Another study of Rajasthan [26] reported that 34.8% of patients of leprosy were illiterate and they said that the leprosy patients should not be allowed to attend social functions like marriage or birthday party

or any other social celebrations in the community and they should not go to cinema, restaurant or utilize public transports. Further they opined that leprosy is due to a curse of God and if a person allows a leprosy patient to live as a part of the community, God may give the same punishment to him.

A study revealed that families with a patient who had deformities faced 10 times higher societal problems than those having patients with no deformities [29].

In India, the Hindus consider deformity resulting from leprosy as divine punishment [30]. A similar view is shared in China where leprosy is considered to be sexually transmitted by contact with a prostitute and a punishment for the moral lapse [31]. In Africa, leprosy is referred to as 'ngara' or 'lepero' in Botswana, implying an association with "bad blood" [32], and as 'qumtina' in Ethiopia, denoting the "state of amputation or mutilation" [33]. Another common belief is that Leprosy is hereditary [34, 35]. This belief is prevalent among people in India, Malaysia, China and Africa. The Nepalese community widely held the belief that leprosy was contagious (64%) or due to a curse from God (9%) or due to both (18%) [36]. In Urban Guyana, leprosy was seen as a process of progressive deterioration and 61% of the respondents indicated that it could never be cured [37]. Other beliefs and theories prevalent among various cultures attribute leprosy to dirty blood, evil spirits, curses, charms, malnourishment, and eating certain foods.

A study in Chandigarh [38] reported various beliefs and perceptions about leprosy of the respondents in the form of case reports. **Ram**, 49 years of age, did not know that *kushta* and *kodh* referred to the same ailment. He denied being infected with leprosy as, "*Leprosy is a disease of sin and misdeeds, but I have never committed any sin*". Since his hands and body were 'not rotting, as is usual in *kodh*', he believed that he had some nerve disease, but if it were *kodh* after all, then it could be the result of misdeeds committed in his previous life.

Sunil, 45 years old, said that when he got infected with leprosy, he did not know anything about it. He had never heard of the terms *kushta* or leprosy. After the diagnosis, he came to know that *rog* in his native language meant the same as *kushta*. The respondents generally identified leprosy as a disease in which limbs become disfigured. The general phrases used were, '*Haath, paoon gal jaate hain...*' (Hands and feet are rotten...), '*Aur phir rogi ko kodhi ka naam de diya jata hai*' (and then the diseased is given the name of a *kodhi*). One of the respondents narrated that, '*Kodhi ka rog jaldi-jaldi badta jata hai aur yeh hi 'ghrina' (stigmatisation) ka sabse bada kaaran banta hai. Kodh ko log paap ki bimari aur bhagwan dwara di gyi sazaa samjha jaata hai*'. More than two-thirds

(67.8%) of the respondents believed that leprosy was transmitted from an infected person to a healthy one through sharing food and drinks. Sharing of utensils with an infected person, contact with the person's sweat, mosquito or insect bites and sexual contact with a person with leprosy, were also regarded as modes of transmission.

CONCLUSION

A review of the literature showed that the stigma, misconceptions and negative attitudes towards leprosy patients are prevalent in most communities. Most misconceptions pertaining to leprosy, in particular the beliefs in heredity, evil spirits and contact with prostitutes as causes of leprosy, were found to be most common. In addition, deformities arising as a consequence of untreated leprosy played a significant part in increasing the stigma to leprosy. Spouses should also be involved in leprosy control activities. Children can also play a role in disseminating health messages and influencing family members to seek early treatment. Attention should be paid to the training of health-care providers in communication and counselling skills. Health providers must learn to empathise, listen to patients' concerns and respond to them. The paternalistic approach which is often adopted by health-care providers in managing patients in developing countries, is not only inappropriate, but would deter patients from coming for follow-up treatment. Health providers should also learn problem-solving skills to assess the patients' reasons for defaulting treatment or follow-up and act on them. This means that they should be trained on techniques to analyse and motivate behaviour change.

REFERENCES

- Hosoda, M. (2010). Hansen's disease recoverers as agents of change: a case study in Japan. *Lepr Rev*, 81, 5–16.
- Raj Pracha Samasai Institute. (2003). Proceeding of the meeting on guideline for delay in diagnosis, Chiangmai, Thailand. *Raj Pracha Samasai Institute*, Nonthaburi, Thailand.
- Idawani, C., Yulizar, M., Lever, P., & Varkevisser, C. (2002). Gender, leprosy and leprosy control: A case study in Aceh, Indonesia. *KIT, Amsterdam*.
- Heijnders, M. L. (2004). The dynamics of stigma in leprosy. *Int J Lepr Other Mycobact Dis*, 72, 437–447.
- Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: rethinking concepts and interventions. *Psychol Health Med*, 11, 277–287.
- Predaswat, P. (1992). *Khi Thut. The disease of social loathing. An anthropology of the stigma in rural Northeast Thailand*[PhD thesis]. University of California.
- Rafferty, J. (2005). Curing the stigma of leprosy. *Lepr Rev*, 76, 119–126.

8. Burathoki, K., Varkevisser, C., & Lever, P. (2004). Gender, leprosy and leprosy control: A case study in the far west and eastern development region, Nepal. KIT, Amsterdam.
9. Brown, W. (2006). Can social marketing approaches change community attitudes towards leprosy? *Lepr Rev*, 77, 89-98.
10. Try, L. (2006). Gendered experiences: Marriage and the stigma of leprosy. *Asia Pacific Disability Rehabilitation Journal*, 17, 55-72.
11. The Church of Jesus Christ of Latter-day saint. Leviticus 13-14. Internet 2012 [cited 2012 May 1]; Available from: URL: <http://seminary.lds.org/manuals/old-testament-seminary-student-study-guide/ot-ssg-4-lev-13.asp>
12. Volinn, I. J. (1989). Issues of definitions and their implications: AIDS and leprosy. *Soc Sci Med*, 29, 1157-1162.
13. Entwistle, A. W. (1987). Braj: centre of Krishna pilgrimage. E Forsten, Croningen.
14. Poopook, S., Guptabha, K., & Kachen, S. (2000). Development of model on community based rehabilitation and quality of life improvement for persons affected with leprosy. *Com Dis J*, 26, 160-169.
15. de Stigter, D. H., de, G. L., & Heynders, M. L. (2000). Leprosy: between acceptance and segregation. Community behavior towards persons affected by leprosy in eastern Nepal. *Lepr Rev*, 71, 492-498
16. Buhler, G. (1886). The Laws of Manu. In: The Sacred Books of the East, vol. 25. Oxford: Clarendon Press. Available: <http://www.fordham.edu/halsall/india/manu-full.html>. Accessed 3 April 2007.
17. Bhisagratna, K. K. (1963). The Sushruta Samhita. Varanasi: Chow- khamba Sanskrit Series Office, Volume II. pp 36-40.
18. Wong, M. L. (2004). Designing programmes to address stigma in leprosy: issues and challenges. *Asian Pac Rehab J*, 15, 3 - 12.
19. Waxler, N. E. (1991). Learning to be a leper: a case study in the social construction of illness. In: Mishler EG, Amarasingham, L., Hauser, S. T., Liem, R., & Osherson, S. D. (eds). Social contexts of health, illness, and patient care. *Cambridge University Press, Cambridge*, 169 - 194.
20. Goffman, E. (1963). Stigma: notes on the management of spoiled identity. Prentice-Hall, Englewood Cliffs (New Jersey).
21. Nsagha, D. S., Bissek, A. Z. K., & Nsagha, S. M. (2001). Social Stigma as an epidemiological determinant for leprosy elimination in Cameroon. *J Pub Health Afr*, 2, 38 -44.
22. Van den Broek, J., O'Donoghue, J., & Ishengoma, A. (1998). Evaluation of a sustained 7 year health education campaign on leprosy in Rufiji District in Tanzania. *Lepr Rev*, 69, 57 - 74.
23. Rafferty, J. (2005). Curing the stigma of leprosy. *Lepr Rev*, 76, 119 - 126.
24. Prabhakara Rao, V., Rao, I. R., & Palande, D. D. (2000). Socio-economic rehabilitation programme of LEPRA India -methodology, results and application of needs-based socio-economic evaluation. *Lepr Rev*, 71, 466 - 471.
25. Scott, J. (2000). The psychosocial needs of leprosy patients. *Lepr Rev*, 71, 486 -492.
26. Yadav, S. P. (2011). A Study of Social Status of People with Disabilities due to Leprosy in Desert Part of Rajasthan, India. *J. Commun. Dis*, 43(3), 201-207.
27. Mutatkar, R. K., & Ranade, M. G. (1986). Evaluation of health education in leprosy control programme.:methodological considerations. *SE Asia J Tropical Med Public Health*, 77, 437-441.
28. Crook, N., Ramasubban, R., Samy, A., & Singh, B. (1991). An educational approach to leprosy control: an Evaluation of knowledge, attitudes and practice in two poor localities in Bombay, India. *Lepr Rev*, 62, 395-401.
29. Kopparty, S. N., Kurup, M. A., & Sivaram, M. (1995). Problem and coping strategies of families having patients with and without deformities. *Indian J Lepr*, 67, 133-52.
30. Muthankar, R. K. (1979). Society and Leprosy. Wardha, India: Gandhi Memorial Leprosy Foundation.
31. Skinsnes, O. K. (1964). Leprosy in society I. Leprosy has appeared on the face. *Lepr Rev* 1964, 35, 21-35.
32. Kumaresan, J. A., & Maganu, E. T. (1994). Socio-cultural dimensions of leprosy in North-Western Botswana. *Soc Sci Med*, 39, 537-541.
33. Teckle-Haimanolt, R., Forsgren, L., & Gebre-Mariam, A. (1992). Attitudes of rural people in central Ethiopia towards leprosy and a brief comparison with observation with epilepsy. *Lepr Rev*, 3, 157-168.
34. Chen, P. C. Y. (1986). Human behavioural research applied to the leprosy control programme of Sarawak, Malaysia. *Southeast Asian J Trop Med Public Health*, 17, 421-26.
35. Gussow, Z. (1989). Leprosy, racism and public health: social policy in chronic disease control. London: Westview Press.
36. De Stigter, D. H., de Geus, L., & Heynders, M. L. (2000). Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Lepr Rev*, 71, 492-498.
37. Cook, A. (1982). An urban community's thought about leprosy: A study in Guyana. *Lepr Rev*, 53, 285-296.
38. Singh, S., Sinha, A. K., Banerjee, B. G., & Jaswal, N. (2012). *Knowledge, Beliefs and Perception of Leprosy*, 23(4).