

Knowledge, Beliefs and Perception of Leprosy

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ABSTRACT

Purpose: For intervention to be effective, it is essential that the knowledge, beliefs and perception of a specific social group are taken into account. This is particularly true of leprosy where the problems of social stigma and ostracism are more prominent than the disease itself. There are many misconceptions about the cause, methods of transmission, and treatment.

The main objectives of the study were to examine the socio-demographic profile of persons with leprosy and to explore their knowledge, beliefs and perception about the disease and its initial symptoms, within a specific socio-cultural milieu.

Method: Semi-structured interviews were held with a persons with leprosy at various clinics and care-homes for affected persons in and around Chandigarh, India. Those who had completed their treatment and those who were still undergoing treatment were included in the study. Data collection was done through case studies and in-depth interviews.

Results: The name of the disease varied across different geo-cultural zones. Many respondents who were afflicted with only red patches and had no ulcers, believed that they suffered from a skin disease which would turn into leprosy if proper medication was not received. The perception of 64.9 % of the respondents was that leprosy resulted from supernatural causes like God's punishment, karma, and sin.

Conclusion: There is a need to educate persons with leprosy and their families about the etiology of the disease.

Key words: Leprosy, knowledge, beliefs, perception

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INTRODUCTION

The manner in which people perceive their disease and its treatment determines their health-seeking behaviour (Tipping & Segall, 1995). The understanding of health and illness can vary across different contexts, environments, and cultures. MacLachlan (1997) argued that symptoms of a disease can be 'culture bound'. What can be interpreted as illness in one culture does not have to be so in another culture, and a given disease can have different meanings in different cultures. In other words, two individuals from different cultures, social backgrounds and different contexts may interpret the 'same disease' (such as tuberculosis) or symptom (such as pain) in a completely different manner (Helman, 1994). This will affect their subsequent health-seeking behaviour.

Leprosy is a chronic infectious affliction that poses a great risk of permanent and progressive physical disability. The associated visible deformities and disabilities have contributed to the stigma and discrimination experienced by persons with leprosy (Bryceson & Pfaltzgraff, 1990; Noorden, 1995), even among those who have been cured (Mankar et al, 2011). Much of the stigma associated with leprosy stems from inadequate or incorrect knowledge about the disease and its current treatment (WHO Technical Report, 1997; International Leprosy Association, 2002). Even after nearly two decades of excellent multi-drug therapy and remedies for reaction and ulcers, large segments of the rural population seem ignorant or poorly motivated to seek early treatment (Srinivasan, 1991).

Apart from physical distress, disease causes psychological as well as social distress. It may make the individual lose the ability to cope with day-to-day social functioning. To control any communicable disease, it is very important to have basic knowledge about the perceptions of persons with the disease. Unfortunately people have developed wrong notions regarding leprosy, which is a disease like any other, and persons with leprosy are ostracised by their families and society. It is now an established scientific fact that leprosy can be cured easily with early treatment. Diagnosis at an early stage is absolutely essential, and therefore it is important to be aware of the initial symptoms.

This study attempts to explore the knowledge, beliefs and perception of leprosy by persons with the disease, and the various dimensions of the socio-cultural background to their 'stigmatised' identity.

OBJECTIVE

The main objectives were to:

- Study the socio-demographic profile of persons with leprosy.
- Assess their knowledge, beliefs and perception about leprosy.

METHOD

Qualitative methodology was employed to explore the various dimensions of the problems under study. The case study method and participant observation method were used to collect data. The study sample consisted of 245 persons. Only clinically diagnosed persons (195) who visited leprosy clinics and hospitals for treatment, and those staying (50) in the *Kushtha Ashrams* (leprosy homes) in Chandigarh, India, were included after obtaining informed consent.

In Chandigarh, interviews were conducted with those who were undergoing leprosy treatment at the Postgraduate Institute of Medical Education and Research (PGIMER) the Government Multi-Speciality Hospital, the Polyclinic, and the Civil Dispensary. Each respondent has been taken as a case. A total of 80 cases were collected but only a few have been included to support the data. The respondents' beliefs and perceptions about leprosy have been conveyed in the form of case reports and narratives which have been supplemented with the researchers' observations. Names have been changed to maintain confidentiality.

Socio-demographic Profile

The socio-demographic profile of the study participants reflected that most of them were males (69%). Participants' ages ranged from 27 to 59 years, with a mean age of 38.61 ± 8.95 years. Two-thirds (61%) were Hindus. The majority of the respondents (76.7%) were married. 32.7% of them were illiterate and only 8% had higher education (graduation and post-graduation). More than half (57.1%) belonged to poor socio-economic backgrounds and 27.8% of them were unemployed.

Knowledge, Beliefs and Perception about Leprosy

The understanding of the term 'leprosy' varied from one culture to the other. It was mainly known as "*kushta rog*", and the other names for it were *kodh*, *bada rog* (big disease), *sun bairee* (numbness), *charam rog* (skin disease) and *paap ki bimari*

(a disease of sin). The respondents' beliefs and perceptions about leprosy are explained 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*'. (The spread of leprosy is quick and the visibility of the symptoms becomes one of the major determinants of stigma. Leprosy is perceived as a disease of sin and a punishment given by God).

According to one 30-year-old, every individual has to pay for his *karma*. Wrong deeds in a previous birth, disobedience and non-conformance to one's religion reflect ill effects in one's present life. He believed that he had been suffering from this disease because he had once done something evil. A long time ago, on an outing during his schooldays, he had eaten beef under pressure from his friends. According to Hindu religion the cow is a sacred animal and is regarded as a mother. He thought that he had been punished for that sin with leprosy. He also believed that leprosy could be caused by eating fish together with milk.

Ashok, a 30-year-old, said that he did not know the exact cause and treatment of leprosy. He only believed that leprosy might be caused by having fish and milk together. Eating fish was very common at home, usually along with goat's and cow's milk. Secondly, he believed in the *karma* theory because although all his

family members used to eat fish along with milk, he was the only one who got this disease.

Unlike most rural people, 33-year-old **Bhim** did not believe that leprosy was a consequence of a person's past life *karma*. After learning about the disease, he was convinced that anyone could get leprosy, depending on his/her exposure and resistance or immunity.

Regarding perceptions about the possible cause of leprosy, two-thirds (64.9%) of the respondents attributed it to supernatural causes like *karma*, sin, God's punishment, etc. A person's physical attributes, such as good looks, and intelligence are believed to be the fruits of his/her past *karma*, and not the product of hereditary or biophysical causes. Gender is also decided by *karma*, and in the same way *karma* accounts for whether one is rich or poor. A person who is born with good health is believed to have a good *karma*.

This study found that leprosy is regarded as a form of punishment for wrong actions or deeds committed sometime in the past or present life. Very few respondents believed that leprosy was caused by a bacterium. More than two-fifths (45.7%) believed that skin-to-skin contact with an infectious person could be a possible cause. Breach of taboos and intake of wrong food were regarded as possible reasons, by 39.2% and 37.1% respectively.

Mode of Transmission

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.

Munish, a 30-year-old, strongly believed that leprosy was transmitted mainly through physical contact. He said that in certain circumstances it could be possible for someone to acquire the disease while eating with an infected person. He also believed that children were vulnerable due to their weak immune systems.

Vulnerability to Leprosy

It is significant to note that 74.7% of the respondents stated that people with weak immune systems (susceptible to getting disease), such as children, people

residing in slum areas and following poor hygiene, had a higher chance of contracting leprosy. More than half (52%) of the respondents thought that a person with leprosy could be cured if the disease was diagnosed early and correct and consistent treatment was followed.

Early Signs and Symptoms of Leprosy

70.2% of the respondents reported painless or non-itchy white patches on the body as early signs of leprosy. In addition to white patches, two-thirds also reported anaesthesia, numbness and red patches as early signs. The symptoms of numbness and anaesthesia were confusing and people became aware only after leprosy was diagnosed by the doctors. Another important point is that these reactions sometimes led to severe deformity due to the delay.

Visible Impairment

Disfigurement is invariably associated with leprosy. The moment one hears about someone infected with leprosy, he/she is unconditionally thought of as a person with gross deformities. The respondents were asked about the reason for deformity. The majority (78.4%) responded that delay in seeking treatment leads to deformity. In-depth interviews with respondents revealed that people associated early signs and symptoms of leprosy with other diseases like ringworm and fungal infections, and consequently followed their own methods of treatment. Another important finding was that most of them resorted to alternative courses of treatment like visiting traditional healers, which prevented them from initiating or continuing the treatment recommended by their physicians. This led to further disfigurement.

DISCUSSION

The name of the disease 'leprosy' varied across different geo-cultural zones. Van de Weg et al (1998), in their study of explanatory models and help-seeking behaviour in Nigeria, found that cultural differences in the understanding of sickness and treatments resulted in widely varying choices and outcomes.

This study found that 'leprosy' was perceived to be a curse of God, resulting from the wrong deeds committed sometime in a past or present life. Stereotypes resulting from Indian religious beliefs have long focussed on passivity, inferred from beliefs in fate and karma. A study by Weiss et al (1992) found a strong

association between the belief in fate and karma, and the failure to make use of available help.

The Hindu and Buddhist participants who referred to *karma* – the result of deeds in a previous life – implied a cultural reference to fate; but on enquiry, no one could elaborate on what they might have done or give any specific details. Babb (1983) stressed that an anthropological research on karma in popular Hinduism emphasised “moral responsibility and destiny” as well as the “unpredictability of human fortune in the short run”.

Very few respondents (15.2%) believed that leprosy was caused by a bacterium or germs. This figure was very low in comparison to what was reported in a study of Myanmar (85.7 - 92.5%) (Myint et al, 1992). Another cross-sectional study on the knowledge and perceptions of registered persons with leprosy revealed that knowledge about infectiousness of disease was better among the urban group (78.6%) than the rural group (29.8%) (Srivastava et al, 2011). More than two-fifths (46%) of the respondents in the present study believed that skin-to-skin contact with an infectious person could be a possible cause of leprosy. Breach of taboos and intake of wrong food were regarded as other possible causes, by 39.2% and 37.1% respectively. Mankar et al (2011) found 84.31% of persons with leprosy did not know the mode of transmission.

The majority of the respondents reported painless white patches and numbness as the early signs and symptoms of leprosy. Similar findings were reported in a study by Srivastava et al (2011) in which discolouration of skin patches, sensory alteration and ulcerative lesions on feet and hands were found to be the most commonly known symptoms of leprosy, with better levels of knowledge among affected urban people. In the present study, deformity was found to be invariably associated with leprosy. Research in Myanmar found that community members believed that all leprosy affected persons would inevitably end up with some deformity (Myint et al, 1992), which increased the dread of the disease. In India, the more severe the disability, the greater was the level of stigma (Prabhakara et al, 2000).

In-depth interviews with respondents revealed that initially people confused early signs and symptoms of leprosy with other diseases like ringworm and fungal infection, and followed their own methods of treatment like home remedies or traditional healing. This resulted in delaying correct treatment and led to further deformity. Similar findings have been found in a study by Bekri

et al (1998) conducted in Ethiopia, which showed that misconceptions about the symptoms, low awareness of modern treatment, and the influence of traditional healers or community leaders lead to delay in seeking treatment for leprosy.

CONCLUSION

Different geo-cultural zones had different names for the disease and the respondents identified their illness with a variety of different labels. *Kushta rog* was the most common term, followed by other names like *kodhi*, *bada rog*, *sun bairee* (numbness), *charam rog* (skin disease), and *paap ki bimari* (disease of sin). Regarding perceptions about the possible cause of leprosy, 65% of the respondents perceived supernatural causes like God's punishment, *karma*, and sin. Despite efforts at educating persons with leprosy, very few respondents had understood the concept of bacterial infection.

As the World Health Organisation (2012) has stressed, leprosy is curable and treatment provided in the early stages averts disability. Health education is the key to provide information to affected persons and the general public, to dispel misconceptions about the disease and to create awareness about the importance of early diagnosis and treatment.

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