



Socio - cultural beliefs and stigma including Health seeking behaviour towards Leprosy - A review

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ABSTRACT

Leprosy (Hansen's Disease) is a chronic infectious disease, caused by *M. leprae*. The word leper comes from a Greek word meaning scaly. It affects mainly the peripheral nerves and affects the skin, muscles, the eyes, the nose, bones, testes and internal organs. In some countries, a significant number of cases do not seek treatment or seek treatment late, partly due to socio-cultural beliefs and stigma about leprosy. The priority areas in the leprosy elimination programme are early case detection, case holding and consequently, the prevention of disabilities.

So there is a nation-wide mass education is needed to educate people. This may include social assistance and social support to the patients, help to the needy individuals and families. Such information would help determine the areas of emphasis in an education programme to make people seek early diagnosis and undergo the prolonged treatment for cure.

INTRODUCTION

Leprosy, also known as Hansen's disease (HD), is a chronic infection caused by the *Mycobacterium leprae* and *Mycobacterium lepromatosis*. [1] Leprosy takes its name from the Latin word *Lepra*, while the term "Hansen's Disease" is named after the physician Gerhard Armauer Hansen. It is primarily a granulomatous disease of the peripheral nerves and mucosa of the upper respiratory tract; skin lesions are the primary external sign. [2]

Left untreated, leprosy can be progressive, causing permanent damage to the skin, nerves, limbs and eyes. Deformities can develop when they do not report early for treatment. Effective drugs are available which can cure leprosy completely. If one take early and continues treatment, patients will not only be cured but can also be protected from deformities.

SIGNS OF LEPROSY

However, all skin patch may not be leprosy. One can suspect leprosy when he sees any one or more of the following early signs: a pale or red patch on the skin and change in texture on any part of the body. a raised or flat patch- dry , shiny or smooth a well demarcated patch on the skin when does not burn or pain ,

inability of certain areas of the body to appreciate touch, heat or cold, loss of sensation with or without a patch

PERCEPTION OF THE DISEASE

In India, leprosy is known since ancient times as Kushthroag, Khor or Maharoga and attributed to punishment or curse from almighty God . It is regarded as the most dreadful and least understood of all ailments. A number of beliefs exist about the cause, spread and treatment of leprosy. These beliefs appear to be related to the behavior towards affected individuals.

SOCIAL-CULTURAL BELIEFS ABOUT LEPROSY

Even today, in spite of availability of scientific information about leprosy, the socio- cultural myths and beliefs are deeply rooted in the minds of the most people at all levels of society. The real tragedy with leprosy is that somehow, it got shrouded in deep rooted myths and beliefs right from the ancient times giving rise to inhuman behavior of societies towards leprosy patients. The deformities, disfigurement and mutilations, caused in neglected cases, has reinforced this concept and inspired an aura of dread or horror in some people, resulting in alienation of patients from their societies.

Leprosy patients do not only suffer because of their disease ,

they also suffer because people will not talk to them or may not want to eat or work with them. In some communities, the patients deliberately leaves his family in order to avoid the rejection of society. In addition, he has the content fear that he will transmit his disease to them. He is plagued by fears, fear of being recognized as having leprosy, fear of rejection by his loved ones and fear of persecution by society.

Age, gender, educational level and religion have been found to play a significant role in the beliefs of the patient with respect to leprosy. A study in Tanzania showed that stigmatizing attitudes and beliefs pertaining to leprosy were associated with a low level of education, female gender, rural residence and religion. [3]

BELIEFS RELATED TO CAUSATION ABOUT LEPROSY

There are many different beliefs about the causes of leprosy. Leprosy is often called a “Social diseases”. There are numerous social factors which favour the spread of leprosy in the community such as poverty and poverty related circumstances (e.g. overcrowding, poor housing, lack of education, lack of personal hygiene) and above all, fear , guilt, and unfounded prejudices regarding the disease. Person affected by leprosy experience unsympathetic reactions, insults, hate, and rejection from society. Other beliefs and theories prevalent among various cultures attribute leprosy to dirty blood, evil spirits, curses, charms, malnourishment, and eating certain foods. Misconceptions about the causes of leprosy were also prevalent among health care providers. In a study in Nigeria about two thirds (65%) of the final year nursing students said that leprosy was highly infectious and that deformities were inevitable in leprosy. [4]

In south India, stealing of pumpkin or beating a calf is believed to cause of leprosy. Other think that it is caused by drinking water from the same well or hand pump where leper patient goes for water.

DIVINE PUNISHMENT

The diseases are believed to be caused by supernatural means or by the violation of social tabbos. In certain cultures of the developing countries, leprosy is considered to be a curse and a symbol of wrath of almighty gods and goddesses. A leper is regarded as a sinner.

In India, leprosy is regarded as the most dreadful and least understood of all ailments. The disease is believed to be caused by supernatural means or by the violation of social taboos. The principal belief is related to an individual's misdeeds (Paap) in his previous birth for which he incurs the wrath of Almighty God. [5]

The stigma against Leprosy is partly due to cultural beliefs and misconceptions about the causes of leprosy. In a study in the Kaduna state in Nigeria Muslim patients believed that leprosy is God's will, while Christians perceived it as a punishment for their sins. This may explain why Muslims as compared to other religions better accept leprosy patients. [6]

BELIEFS RELATED TO TRANSMISSION

The mode of transmission of infection through bacteria or germs is not known. It is, however believed that the disease is communicable and the affected individual is the agent of infection. It is believed that Infection spread through direct or indirect physical contact and also through the breath. Nobody talk with him lest they got infected through the air. Shopkeepers do not sell anything to him, lest infection travel through the coin.

Even the floor where he has stood or sat is later washed. In rural areas, the affected individual is either asked to leave the community and seek treatment anywhere, or he is kept in segregation outside the village. There, he is provided with food by one of his family member who is required to take a bath and wash his clothes after the visit. The concept of heredity is also deeply rooted in Indian culture. It is believed that leprosy is hereditary. Hence, there is a hesitancy to marry into a family in which the disease has occurred. It is also believed that leprosy can be transmitted from prostitutes or cohabiting with a menstruating women. This belief is prevalent among people in India, Malaysia, China and Africa. Ironically, even in Norway where Hansen identified the leprosy bacilli, the medical profession firmly believed that leprosy was hereditary and promoted the idea of segregation to prevent procreation. [7]

Since the social structure is based on the principle of hereditary inequality, it makes it difficult to change people's misconceptions about the hereditary nature of leprosy.

BELIEFS RELATED TO PREVENTION

The leprosy disease is believed to spread from the individual himself, preventive action is centered on avoidance and segregation of the patient. He cannot remain with his family or community. They spend the rest of life in the leprosy home or outside their community. Many leprosy patients also experience rejection from the society and are not able to find employment due to the stigma attached to the disease. [8] In a study among health workers in Botswana more than a third of respondents believed that patients should be isolated and treated. [9]

LEPROSY STIGMA AND HEALTH SEEKING BEHAVIOUR

Leprosy stigma has been found to be a major factor leading to the delay in patients seeking treatment. The stigma against leprosy seems to be related to the fact that leprosy deforms and disables but seldom kills, so that those who have been crippled, live on, getting steadily worse, their deformities visible to the whole community. The chronic symptoms of untreated leprosy often afflict individuals in their most productive stage of life and limit or prevent them from fulfilling their normal roles in society: they may lose their economic independence as a result of losing their jobs, their physical independence as a result of disabilities, their self esteem as a result of social isolation and generally live a lower quality of life. [10] Persons affected by leprosy experience unsympathetic reactions, insults, hate and rejection from society. [11] The stigmatization in leprosy is frequently extended to the families having members suffering from leprosy. A study revealed that families with a patient who had deformities faced ten times higher societal problems than those having patients with no deformities. [12]

BELIEFS RELATED TO CURE

It is believed that there is no permanent cure for the disease. This belief of “one leper always a leper” completes the social ostracism of the affected individual.

The disease is regarded as a minor skin ailment and hence, not disclosed to others. The symptoms attributed to dryness are likewise not regarded as leprosy. The loss of sensation, however, creates a suspicion of something serious and the matter now continues to be hidden from others for an entirely different reason- the fear of social repercussions. Indigenous sources are tried for the leprosy disease. The affected parts are massaged

with mustered oil or neem oil (oil of margosa) and application of honey mixed with cow's milk.

The health-care seeking behaviour of people affected by leprosy is influenced by many factors, including the patient's and the society's beliefs and perceptions about leprosy; the availability, accessibility, acceptability and affordability of health services, quality of the health-care provider-patient relationship and the patient's socio-demographic characteristics. In a society, which discriminates against leprosy sufferers, patients would conceal their condition and not seek or adhere to the treatment for fear of, or as a result of social rejection. [13] Previous research showed that health seeking behaviour of leprosy patients typically followed a pattern of home based care with over-the-counter medications, followed by consultations with traditional healers and finally approaching the local health facility. [14]

Delay in identifying symptoms and presenting for treatment was also found to be higher among females. [15]

More females than males also resorted to "home remedies" such as fasting and offerings to God, as well as native treatment given by traditional healers prior to seeking medical treatment. Some countries are beginning to work with traditional and religious healers to provide care to leprosy patients, probably because many patients consult them first before seeking treatment from western health-care systems. A study in Nigeria showed 59% of the patients consulted the folk-medicine sector as the first step in their health seeking routine. [16]

Studies in Botswana demonstrated the harmonious coexistence of modern health-care workers and traditional and religious healers even though the latter harbored superstitious beliefs as to the cause of the disease. [17]

RECOMMENDATION

Persons affected by leprosy experience unsympathetic reaction, insults, hate, segregation and rejection from the society. The deep rooted socio-cultural factors cannot be banished overnight and no anti leprosy campaign is complete without health education. Health education and proper counseling should be directed towards the patient and his family about the need for regular treatment, repeated medical examination, follow ups, self care, prevention of disabilities etc.

The general public should be made aware about leprosy on the true facts about leprosy and remove superstitions and wrong beliefs and the social stigma associated with leprosy. Educate the family and society to accept the patient as having simply a disease which is treatable and which is less contagious than most others they are familiar with. Educate them to accept responsibility for the patients in society and not in segregation, and for the dependents of the patients during the time he himself cannot provide for them.

A nation-wide mass education is needed to educate people. This may include social assistance and social support to the patients, help to the needy individuals and families.

Based on the review, recommendations are proposed on how socio-cultural dimensions may be incorporated into leprosy control programmes to reduce stigma and fear about leprosy patients and increase community acceptance of leprosy patients.

The most humane, most economic and safest way to care for children of patients with leprosy is far them to live with their parents. If the stigma related to the disease is reduced, community members are also more likely to seek early treatment.

Studies should also be conducted among health care providers to assess their beliefs and attitudes on leprosy.

The primary objectives of community health education interventions are to inform the community about the effectiveness of treatment, counteract the stigma and promote integration of affected persons and their families. Misconceptions are difficult to dispel and cultural beliefs are very resistant to change. Thus, it is important to integrate the true facts about the disease, such as its curability and non-infectivity, into the local community's existing beliefs. The campaign should provide accurate knowledge of leprosy by working its way around the misconception rather than denouncing the traditional beliefs outright. A multi-sectoral approach that involves health professionals, community and religious leaders as well as governmental representatives in all stages of planning and delivery of community health education programmes and other leprosy control activities is recommended to ensure better impact, continuity and wider acceptance of the intended health messages. Spouses should also be involved in leprosy control activities, as they can play an important role in case finding particularly among Muslim female patients who donned the 'purdah' as a religious practice.

The feasibility and acceptability of involving traditional healers should be explored to encourage lay referral. This is important particularly in communities where a significant proportion of leprosy patients sought traditional healers prior to seeking treatment from health facilities. Conduct cross-cultural comparison studies.

The leprosy patients need maximum psychological support. The family should be visited and reassured and its help solicited. In this way, the education of the public as whole is furthered.

CONCLUSION

This review article suggested that the stigma, misconception and negative attitudes towards leprosy patients is a common among people. Most misconceptions pertaining to leprosy, in particular the beliefs in heredity, evil spirits and contact with prostitutes as cause of leprosy which found to be rather similar across wide geographical and cultural backgrounds. In addition, deformities, arising as a consequence of untreated leprosy played a significant part in increasing the stigma to leprosy. The fact that the medical world knows that leprosy is curable. But in the battle to overcome leprosy, the real challenges lies in overcoming the fear and horror that people feel at a very mention of the diseases.

If only we could make people understand that the complications which arise from leprosy are the effect of neglect, and that they can be prevented if the disease is detected and treated in time. This would be a giant step forward towards overcoming the fear of leprosy which is the biggest barrier to its management.

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