

SOCIAL STIGMA IN LEPROSY

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ABSTRACT:

Leprosy is a disease associated with a strong social stigma and fear. This is due to the disfigurements and crippling which it causes, resulting in socio-economic hardships for the victims. Also, misconceptions and erroneous beliefs about leprosy abound, even now, and in almost all the sections of the population. The human and social impact and the age-old prejudices against the disease add insult to injury. Even the law, and media have played a very damaging role for the leprosy patients by perpetuating the stigma of leprosy. The strategy for elimination of leprosy must specially stress on the psycho-social aspects of the disease and also the rehabilitation of the leprosy patient in the home, work place and society. There is absolutely no need to regard leprosy as 'special' and the well-being of leprosy patients should become an integral part of the general health services of the community.

Social stigma in leprosy

Leprosy is a disease of antiquity, as ancient as the civilization of man, a scourge of mankind, and, yet, it remains one of the least understood diseases. Of all communicable diseases, leprosy is the most unique for its sheer potential to cause permanent physical, mental, social and psychological damage to an individual or a society. From the earliest times, leprosy has been a disease set apart from all others, and in a great many communities, its sufferers and even those who care for them have been rejected by society. For these and other reasons, the enormous progress that has been made in medicine in this century has, until recently, passed leprosy by, and the few who devoted their lives to this disease have had to make do with inadequate staff, money, research or acknowledgement. The many enigmas of the disease still constitute a challenge to medicine.

Stigma

Leprosy has always attracted a high degree of social stigma, which is as old as the disease itself, and is the major hindrance in the control of leprosy.

'Stigma' has been defined as an attribute that is deeply discrediting, and the stigmatized individual is one who is not accepted and not accorded the respect and regard of his peers, one who is disqualified from full social acceptances¹. It has been said "The problem with leprosy is not what the disease is, but what the people believe it to be." There is no other disease so associated with stigma and fear, and this seems to be related to the fact that leprosy deforms and disables but seldom kills, so that those it has crippled live on getting steadily worse, and yet for all to see.²

Misconceptions in leprosy

Leprosy has for long remained a disease with a lot of misconceptions, erroneous ideas, superstitions and misrepresentation, attached to it. Leprosy was previously considered a curse, a visitation or punishment from God for the past sins of the sufferer. It was believed that leprosy was incurable, 'once a leper, always a leper' was the dictum. It was also thought that the disease was congenital and hereditary. The loathsome appearance of the patients led to the myth of leprosy being highly infectious and contagious.

Impact of leprosy stigma on patients and society

Leprosy patients have always been subject to severe ostracism. The attitude of society towards those suffering from leprosy has given rise to many unfortunate incidents of insult, rejection and even murder of patients, and in some societies these still continue.² As for the patients themselves, they respond in various ways to the attitude society takes toward them. Some admit and accept the disease as their misfortune, and retreat themselves into a shell to avoid exposing themselves and their family members to an ignorantly hostile society³. Some others take an attitude of anger and aggression towards mankind in general for the unjust persecution, or they take the role of the 'clown' to cope with the embarrassment caused by their unusual appearance. Occasionally, they take their own lives as their only release from suffering².

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Stigma in India

In India, leprosy stigma has been very strong and deep. The Hindu view considered leprosy a divine punishment, a highly infectious and incurable disease, frequently associated with deformed beggars. The concept of heredity, deeply rooted in Indian culture (since the social structure is based on the principle of hereditary inequality), has made it difficult to change people's misconceptions about the hereditary nature of leprosy.⁴

In olden days, lepers were given bells to indicate their movements, and people used to move away from their path.³ In Manu Smriti, an ancient Indian text, Manu opined that a person who gave his daughter suffering from 'Kushta' (leprosy) in marriage after openly declaring the fact was not liable to punishment.⁵

Even today, it is next to impossible to get the children of leprosy patients married into healthy families. The stigma sticks to the patient and his family like a permanent scar which cannot be removed.³

Stigma in Western world

The condition of leprosy patients in the Western world has been no better, till recently. The moral judgment of the victims of leprosy was ambiguous, for, on the one hand, it assigned a state of sin to the leprosy patient, but at the same time, considered him blessed for being able to expiate at least part of that sin while still in this life.⁶ For Christian and Jewish communities, the use of the word 'leprosy' in the Bible has been interpreted as a punishment for sin. Shameful and degrading laws were inflicted upon persons suffering from leprosy. They were considered by the society and the Church as 'unclean', were denied civil rights and were expected to dwell in a lazaret house or hospital situated 'outside the camp' (outside the city wall).^{7,8} The patients were not allowed to touch even their own children; and they could not enter a house, an inn, a church, a market nor share the cemetery with those unaffected.^{6,8}

Basically, a person declared to have leprosy had three choices. If he / she was wealthy, seclusion at home was acceptable. For those not so favored, entry into a leprosarium or a life of wandering, begging, stealing and trying to survive in a sea of hostility were the only remaining choices. The Church devel-

oped an elaborate ceremony, by which a person was declared to be a 'leper', and was then excluded from almost all contact with other persons. Legally, such persons were dead. Life as a wanderer was hard at best, and life in a leprosarium was a quasi-monastic existence with a strict set of diet, clothing and activities. A person who did not abide by the rules of a leprosarium could be ejected and forced to take to a wandering life.⁸

The stigma of leprosy was strongly prevalent in the Arab world too. The Hadith, (sayings of the Holy Prophet (peace be upon him)) also advised common people to run away from a leper as they would run away from a lion, lest they catch the dreaded disease.⁹

Leprosy and the law

Even the law is against leprosy patients. There are 4 laws (The India Christians Marriage Act of 1872, Muslim Marriage Act of 1934, Special Marriage Act of 1954 and The Hindu Marriage Act, 1955) concerning marriages which recognize leprosy ('virulent' and 'incurable' leprosy) as a sufficient legal ground for divorce.^{10,11} There are laws debarring women patients from claiming alimony after divorce. There are laws which prohibit leprosy patients from inheriting property, driving a motor vehicle, rights of tenancy, life insurance, recruitment in defence services and standing for elections.¹¹ Hence, the laws, instead of moulding public opinion, have played a very discouraging role for leprosy patients.

Writers, journalists and politicians also promote stigma when they use the words 'leprosy', 'leper' or 'leprous' to imply something evil, degrading or immoral.¹²

Problems faced by leprosy patients

Patients have to face a lot of problems due to the stigma of leprosy. Kant reported that education of student patients was disrupted, 16.7% patients had incurred debt for the diagnosis and treatment of the disease and 58.0% of the patients experienced difficulty in their work due to social ostracism. 10% of the patients could not marry because of their disease.¹³ Tyagi and Jesupadam observed that it was next to impossible to get the children of leprosy patients married into healthy families.³ Divorce because of leprosy was seen in 5.2% patients.¹³ Kaur and Dhar reported divorce in 44.4% cases.¹⁴

Elimination of leprosy

The 44th World Health Assembly in May 1991 adopted a resolution on the elimination of leprosy as a public health problem by the year 2000 A.D., and defined this elimination as a level of prevalence of less than 1 case per 10,000 population.¹⁵

Elimination as a public health problem refers to reduction of disease prevalence to very low levels even if complete interruption of transmission is not possible. When such low levels are reached, the transmission will be so minimal, that the disease will eventually die out. Although the WHA resolution refers to global elimination, it is implicit that it should also occur at regional and national levels.¹⁶ Besides reducing the prevalence of leprosy, a very important benefit of elimination would be reduced new disability and reduced stigma.

Anti - leprosy activities in India

National Leprosy Eradication Programme in India is committed to achieve arrest of the disease by 2000 A.D. The present strategy of leprosy elimination includes early detection of cases and their prompt and regular treatment with multi - drug therapy (MDT), education of patients and the community about curability of the disease, and stresses on their socio - medical rehabilitation.¹⁷

About 285 voluntary organizations are also actively engaged in leprosy relief services. The Government of India has recently repealed the Leper's Act of 1898 which discriminated leprosy patients and perpetuated social stigma.¹⁸ Re-orientation of the conventional methods of information, education and communication (IEC) for spreading knowledge about leprosy would yield better results in eliminating the disease and its stigma.

CONCLUSION

Leprosy patients have been treated with feelings of emotional loathing and revulsion throughout human history in all countries throughout the world. Unfortunately, even today, leprosy still evokes a very strong negative reaction in people, even the educated ones, and shamefully, in doctors too, who come in contact with leprosy patients. Any leprosy control programme, howsoever well laid out and implemented, that meets only the physical and medical needs of leprosy patients, without addressing the psycho - social difficulties faced by these unfortunate persons, and their rehabilitation in the society, is bound to fail,

or at best achieve only partial control of the ugly disease. Therefore, it is high time, that a humane and balanced outlook be adopted towards leprosy and its patients, and it be accepted as simply another disorder that requires medical attention.

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