Review Article on Leprosy Stigma

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Abstract.

Leprosy is more a social problem rather than just a medical disease. Large numbers of leprosy patients beg on the places of worship. Leprosy infected people are thought of as cursed or victims of witchcraft, or as blameworthy/immoral; and their disease well deserved. Leprosy remains one of the foremost causes of crippling deformities responsible for much of the social stigma. One of the consequences of disability and handicap is loss of earning capacity and some patients in the absence of well planned rehabilitation programme, take to begging as a means to make a living. Mental disorders are common in these patients. Due to disturbed mental health patient may commit suicide. The history of leprosy stigma is as old as the history of leprosy. 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. The people should be given health education by medical staff and myths should be removed. This study is done to review the literature related to myths and stigma associated with leprosy.

KEY WORDS: stigma, beliefs, leprosy

INTRODUCTION

Leprosy stigma is a kind of social stigma, a strong feeling that a leprosy patient is shameful and is not accepted normally in society. It is also called leprosy-related stigma, leprostigma, and stigma of leprosy. Leprosy is more a social problem rather than just a medical disease. Large numbers of leprosy patients beg on the places of worship. From ancient times the disease was feared because of the disfigurement it caused and lack of understanding about how it was transmitted; it was long believed to be inherited and was associated with ideas of "unclean blood". In medieval times in Japan, leprosy patients lived apart, settling around temples or shrines, where they begged for charity from passers-by. Starting in 1909, the government required leprosy patients to be hospitalized in the leprosy sanatoria, believing this would prevent transmission of the disease. In some cases, patients were forcibly taken to the sanatoria and their houses were disinfected in the presence of neighbors. Their families were also affected by leprosy stigma. Some patients attempted suicide. The law lasted until 1996. Stigma is a central feature of the social impact of leprosy[1]. Social constructions of leprosy are commonly guided by cultural, traditional and religious beliefs or myths about disease and illness[2,3]; not least in low resource settings like India [4] and many African countries[5]. Too often, leprosy infected people are thought of as cursed or victims of witchcraft, or as blameworthy/immoral; and their disease well deserved[6]. This study is done to review the literature related to myths and stigma associated with leprosy.

REVIEW OF LITERATURE

Even to this day, when leprosy is completely curable with MDT, some parts of India uphold the belief that leprosy is a divine curse, a punishment of past sins, and a result of immoral sexual behaviour. Leprosy was conceived of as a punishment for sin[7]. Leprosy remains one of the foremost causes of crippling deformities responsible for much of the social stigma. One of the consequences of disability and handicap is loss of earning capacity and some patients in the absence of well planned rehabilitation programme, take to begging as a means to make a living[8]. In India
leprosy patients residing in self settled colonies are forced to go to begging due to lack of social support services. When a woman suffers from leprosy it has adverse effect on the family as a whole, emotional bonding with children, child rearing and breast feeding practices[9]. Mental disorders are common in these patients[10]. Due to disturbed mental health patient may commit suicide. The history of leprosy stigma is as old as the history of leprosy. In Western Europe it reached its peak in the Middle Ages since the Church considered leprosy as “unclean”, and many “lazar houses” were built. Patients had carried bells to signal their presence. Since leprosy was found infectious, another kind of cause worsened leprosy stigma. In Japan, forced segregation strengthened leprosy stigma. Leprosy stigma has been universal, has been present in all parts where leprosy was present, except in Norway where in-patient leprosy patients were treated humanely.

There are evidences suggesting ex-leprosy patients were denied of hotel reservations because of leprosy stigma. But people had divergent opinion on this issue indicating there were people with leprosy stigma, as well as people without it. Marriage is difficult and acceptance is not total. Under present Indian law, leprosy is still a ground for divorce. Muslim Marriage Act (1939), Special marriage Act (1954) and Hindu Marriage Act (1954) provide clauses for separation and divorce on grounds of spouse suffering from the disease. Bombay prevention of begging act (1959) favours discrimination against leprosy patients[11].

Many leprosy patients conceal the disease even from their dear and near ones and willingly undergo psychological and physical suffering due to fear of rejection. Even those who start the treatment they are not comfortable due to discoloration caused by clofazimine which is completely reversible and the skin returns to its normal colour with a year. Attitude of concealing is more pronounced in illiterate patients. Depression is the principle factor among various psychological consequences suffered by leprosy patient due to fear of degradation in social status of the family and is more when compared to normal population. Even in the present time people with leprosy have to leave their villages or socially isolated[12].

Another study in Chandigarh[13] reported that leprosy 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). There were various case reports of patients showing various narrations. One of the respondents narrated that, 'Kodhi ka rog jaldi-jaldi badta hai aur yeh hi 'ghrina' (stigmatisation) ka sabse bada kaaran banta hai. Kodh ko log paap ki bimari aur bhagwan dwara di gyi saaza 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. 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. More than twofifths (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.

**CONCLUSION:**

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. The people should be given health education by medical staff and myths should be removed. The community health workers should give proper health education to people. Separate skin clinic should be opened at the centres and skin specialists should be there at the clinics. Understanding how belief of myths
and misconceptions about skin diseases in a community—in the aggregate, as well as among individuals—is important for the development of programs and policies. Education programs are needed to dispel common myths and misconceptions.

REFERENCES