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**Original Research Paper** 



# Stigma and Psychological Problems Encountered By People with Leprosy and How Counselling Helps: A Systematic Review

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### **ABSTRACT**

Leprosy is a medico-social problem with a declining in its medical form due to the presence of effective treatment (MDT) but its social aspect in term of stigmatization, disability, deformities, loss of self-respect and loss of self-esteem and ostracizing of affected ones and misconception of the disease by the community have been well identified as a major threat, therefore, making patients more vulnerable to destitution and social isolation. An important challenge in the post-elimination era of the World Health Organization's Leprosy Elimination Programme is the social integration of leprosy patients into the community since they often suffer rejection due to the stigma attached to leprosy. Leprosy is one of the oldest diseases known to mankind. However, it still continues to be a serious public health problem in the developing world. This is primarily because leprosy is a medical problem with grave social overtones since permanent and progressive disability and consequent psychological damage is a recognized sequel of untreated leprosy. Hence, leprosy, irrespective of the occurrence of deformities, often results in intense stigma and social discrimination of patients and their families and the community at large. Social stigma has a significant role in inducement of psychological disorders in patients with Leprosy. Today, the highest burden of leprosy is concentrated mainly in India, Brazil, Myanmar, Madagascar, Nepal and Mozambique. These countries account for about 83 % of the prevalence worldwide. The study was carried out to determine the Stigma of leprosy disease and perceived psychological impact of the disease in the society. It was concluded that health education and information should be paramount when caring for the patient with leprosy because of the psychological disorders.

**Keywords:** Stigma, Psychological Problems, Leprosy

Infectious diseases can be grouped into two categories, acute and chronic. Chronic diseases often result in long-term physical and social effects. Leprosy is a chronic disease which can be traced back thousands of years. Leprosy is a disease, which strikes fear in the society as a

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mutilating, disfiguring, contagious and incurable disease. Leprosy has been a highly stigmatizing disease for centuries because it causes physical disfigurement and no cure being available until the 20th century. It was described in an Egyptian Papyrus document written around 1550 B.C. Indian writings around 600 B.C. describe a disease that resembles leprosy. It is believed that leprosy was brought to Europe by the army of Alexander the Great after coming back from India. At that time, neither the biological cause nor treatment of the disease was known. Thus leprosy patients developed severe skin conditions and disabilities that terrified people. The number of cases of leprosy worldwide has fallen dramatically in recent years, and in 1991 the world health organization (WHO) declared its aim to eliminate leprosy as public health problem by the year 2000. while there was great hope for the success of this effort, critical questions remain unanswered. Social, economic, and political conditions in endemic countries may complicate efforts to eliminate leprosy. It is also unclear whether the stigma associated with leprosy, a significant factor in discouraging infected people from seeking early and regular treatment, is actually decreasing. Finally, we lack a full understanding of the quality of life of leprosy sufferers in their own communities, in terms of physical, emotional, psychological and social functioning.

Leprosy continues to be a serious public health problem in the developing countries. The population at risk of contracting the disease is large, and more than one-third of all people face the threat of progressive and sometimes permanent physical and social disabilities (WHO 1989).

Only a few of these countries have developed satisfactory health education and rehabilitation programmes designed to combat the stigma of leprosy and to rehabilitate patients. Despite the scientific information successful treatment now available for leprosy, fear and prejudice associated with the condition remain strong in many countries. Leprosy stigma is a kind of social stigma, a strong feeling that a leprosy patient is shameful and is not accepted normally in society. In most societies, leprosy is still viewed as a debilitating, incurable, and socially ostracized disease. For this reason, we need continuing intercultural and cross cultural studies concerning the stigma of leprosy. No disease has been more closely associated with stigma than leprosy, and it has become a metaphor for stigma. Persons affected by leprosy were forced to leave their home and live in segregated areas and suffer economic and social losses (participation restrictions) causing physical and emotional distress. This is the only disease where the sufferer had to live in separate colonies, villages.

At present, Mycobacterium leprae, which was discovered by Gerhard Henrik Armauer Hansen of Norway in 1873, is widely known as the cause of leprosy. Effective, relatively short-duration treatment is available nowadays in the form of multidrug therapy (MDT). However, the stigma attached to leprosy still persists in most countries. Stigma is a serious obstacle to case finding and to the effectiveness of treatment, which are the major concern of disease control programs. Many attempts have been made to reduce the stigma attached to leprosy. For instance, leprosy services have been integrated into the general health care

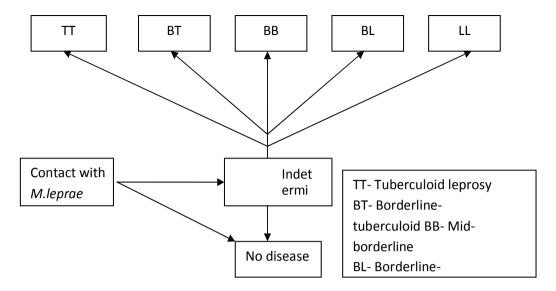
system to reduce the differences between people affected by leprosy and those suffering from other health conditions. Alternative terms have been used instead of 'leprosy', such as 'numbing skin disease' or 'Hansen's disease'. A large budget has been used in the effort to reduce stigma through information dissemination. Although it has been shown that this approach may help to address fear and consequent discrimination related to the biological realities of leprosy, it is unlikely to affect the rejection and alienation due to the attribution of blame. Most stigma reduction programmes have been applied in a blanket fashion, which contradicts the reality that the characteristics of stigma, in particular the determinants, may be different in one society from those in others. It was recommended by Dijker and Kooman that interventions aiming to reduce stigma should be tailored to the type of condition, type of society and type of individuals involved. This is because these factors determine the major motivational systems that affect people's responses to perceived deviance. Gussow and Tracy suggested that it is also essential to understand the social history, current cultural meaning and the 'world-view' of the people involved.

### Medical aspects of Leprosy

Leprosy is a chronic, infectious disease that is caused by the microorganism Mycobacterium leprae (M.leprae). The incubation period is normally about 2-10 years but periods of up to 27 years have been recorded. The mode of transmission is mainly via Nasal droplets from multibacillary patients. M.Leprae is regarded as nontoxic, so patients with active leprosy may harbour millions bacilli yet remain active and apparently healthy. The clinical signs of the disease are largely the result of the host response to the infection. The host-parasite relationship in the leprosy is often unstable. Variations in the Cell-Mediated Immunity(CMI) and immune complex formation can cause clinical manifestations, called reactions, that are not directly related to the bacteriological process.

Up to 75 percent of cases may be self-healing leprosy, which results from an effective immune response. If CMI cannot cope with the bacillary invasion, visible clinical disease results. Classification of disease type is generally along a spectrum according to the patient's CMI and is inferred from the numbers of bacilli found in skin and Nasal smears. A five-group classification of leprosy is proposed by Ridley & Jopling(1962):Tuberculoid Leprosy (TT) is characterized by a more Successful CMI response,Localised lesions, and very few bacilli, found mainly in the nerves.Lepromatous leprosy (LL), on the other hand,is characterized by diffuse and generalized disease,high bacillary load, and more impaired CMI response.Between these two forms of the disease are the immunologically unstable borderline forms-borderline Tuberculoid (BT) and borderline Lepromatous (BL), and mid-borderline form(BB),which shows features of both BT and BL(Duncan, 1993:458).

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**Reactions** in leprosy are clinical manifestations caused by alterations in the immune status of the patient. There are two types of reactions:type1 leprosy (reversal) reaction(RR) and type 2 reactions or erythema nodosum leprosy(ENL). Type 1 leprosy reaction may involve either skin or nerve lesions with resulting neuritis, nerve damage, and permanent deformity. Type 2 reaction is characterized by painful red nodules of the skin that may ulcerate, accompanied by high fever, headache, generalized aches and pains, tender nerves, swollen and tender hands and joints, and so forth(Duncan,1993:459).

M.leprae affects the nervous system, creates skin damage, and anaesthetised and paralyzes parts of the body. Thus can lead to injuries and further infections that may result in deformities if untreated. Leprosy generally begins with formation of pale or reddish patches on the skin. Patches can also be associated with a local loss of sensation. If untreated, red nodules and thickening of the skin may develop. Due to damage to the peripheral nerves, hands may become claw shaped, feet may become deformed, and paralysis of the eye muscles can prevent the lids from closing. This in turn, results in the cornea become ulcerated. The eyes are easily infected and inflamed, and blindness can follow (Duncan, 1993:458). Accidental injury to insensitive hands and feet during activities of daily living often results in wounds. Painless ulcers can become secondarily infected, and osteomyelitis sets in as infection spreads to involve the small bones of hands and feet as a result, loss of fingers and toes may occur, and legs and arms may even have to be amputated. Leprosy is completely curable and deformities can be totally prevented if early multi-drug therapy is taken.

#### Leprosy in Indian Scenario

Leprosy still remains a major public health hazard in India. The country accounts for about one third of the leprosy cases in the world, and has by far the largest number of registered cases among individual countries. Due to migration, leprosy is increasingly being seen in urban areas in India. The states/UTs that have the dubious distinction of a higher than

national average are Orissa, Bihar, Jharkhand, West Bengal, Tamil Nadu, Nagaland, Assam, Madhya Pradesh and Daman and Diu.

#### The concept of stigma

Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people (Jones et al., 1984).25 These individuals were to be avoided, particularly in public places. The word was later applied to other personal attributes that are considered shameful or discrediting. In relation to health, stigma was defined by Erving Goffman as an attribute that signifies that an individual is different from 'normal' people and, further, that the person is 'of a less desirable kind—in the extreme, a person who is bad, or dangerous or weak. Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation; those results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. Fear of stigma, and the resulting discrimination, discourages individuals and their families from seeking the help they need. Stafford and Scott proposed that stigma is "a characteristic of a person that is contrary to a norm of a social group or unit". They defined 'norm' as a "shared belief that a person ought to behave in a certain way at a certain time". Crocker et al. said that "stigmatized individuals possess or are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context". Parker and Aggleton defined stigma as "a social process that involves identifying and using difference between groups of people to create and legitimise social hierarchies and inequalities". Weiss and Ramakrishna defined stigma as "a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem".

#### Determinants of stigma

- 1. **Lack of knowledge**: Lack of knowledge about aetiology & curability, spread of the disease and whether it is hereditary or not, counts for irrational behaviour. Even educated and respected persons can become victim of misconception about leprosy
- 2. **Attitude**: Attitudes are powerful determinant of stigma. Attitudes are learned responses and are manifestations of socially shared past experiences and often defined in terms of beliefs (evaluation), affects (feelings) and behaviour tendency.
- 3. **Fear**: Fear is a major driving force of stigma. Fear of the risk of transmission of the disease is often seen even in doctors and other health workers who are not used to working with leprosy.
- 4. **Blame and shame**: Behaviour of the people strongly influenced by attitudes and beliefs prevailing in the society. Being part of the same community and culture, people feel ashamed of having leprosy because they are blamed for having done something very bad to be punished in this way and suffering for their own fault". For this reason people conceal the diagnosis as long as possible. People internalize these feelings and start

withdrawing themselves from social participation. People abandon their own family, because they fear that their presence will have serious negative effects on the family.

#### Stigma and Hansen's disease

Leprosy has long been described as a disease that destroys not only the body but also the soul; a disease that slowly turns a person into a 'thing' (Valencia, 1983). Leprosy affects many problems like avoidance, negligence, separation, torture and less respect in society etc. because of which affected people hide their disease and do not seek treatment. Hiding disease may relieve their anxiety initially but leads to unavoidable sufferings because treatable condition remains untreated, progresses and reaches a stage when it is no more treatable, to cause unavoidable suffering to the affected person. Leprosy and its stigma have a pervading effect on patients' life affecting marriage, interpersonal relationship, employment, leisure activities as well as participation in religious and social activities. Society maintains negative feelings toward people with Hansen's disease. Problems of divorce, unemployment and displacement from area of residence are common in people affected with Hansen's disease. Stigma attached to these patients has more impact on educated women belonging to a higher socioeconomic group and in joint families. Because of the fear of infecting family members, women sufferers keep themselves aloof and are constantly worried about divorce. Stigma resulting in discrimination and social exclusion can have a major impact on quality of life. Self- stigma causes people to hide their condition or to withdraw from normal social participation. The psychosocial issues that are commonly related to stigma are people's dignity, social status, employment opportunities, job security, family relationships, and friendships. People have left their families and even spouses and children, fearing the repercussions of the fact that they had Hansen's disease. Discriminative attitudes were more common in joint than nuclear families. Raju and Kopparty in a study found that lack of knowledge, understanding, and incorrect beliefs regarding Hansen's disease are responsible for continuation of the stigma cycle. Leprosy does not only affect day-to-day functioning in the family, but considerable restrictions are imposed on patients due to the fear of social stigma. It is substantiated by the fact that the divorce rate among the leprosy sufferers is relatively high. Stigma refers the way sufferers feel, or perceive themselves to be at the receiving end of stigma. This usually includes reduced self-esteem ("I am no good"; "no one will want to marry a person affected by leprosy like myself"), hopelessness ("I can no longer probably my own fault that I have developed leprosy").

#### Stigma associated with other Public Health Problems

Stigma creates a barrier between the sick and rest of the society that prevents them from acting on their instinctive desire to seek curative treatment that will enable them to re-enter into their everyday social activity. Stigmas do not increase the ability of modern Societies to survive infectious diseases, but in fact may be important drivers of problematic disease dynamics and act as catalysts for failures in protecting public health. Evolutionary psychologist argue that all stigmas and stigmatization Processes evolved from disease-

avoidance mechanisms (Park, Faulker, & Schaller,2003), Highlighting the fundamental connection between disease and stigmas.

Stigma & Discrimination remain serious barriers to care for people with HIV/AIDS & Tuberculosis, among other illness. Stigma profoundly affects the lives of individual living with HIV& TB and those of risk of HIV infection. Studies of HIV positive people in the India have demonstrated a relationship between stigma and multiple health related outcomes, including poor ART adherence, health related qualities of life and increased HIV symptoms and depression. Disease related stigma has a deleterious effect on victim's psycho emotional capacity. Although valuable theoretical model of stigma exist in the social science literature, our understanding of the mechanism of how and why stigma may affect health and healthcare and what can be done to mitigate the impact of stigma on the health and quality of life. Stigma and consequent discrimination have a double impact on TB control. In this systematic review, we examined the existing literature on how HIV/AIDS & TB stigma is conceptualized, the methodologies for measuring stigma, and the available data on the relationship of stigma to the effectiveness of HIV & TB prevention and treatment programs, and interventions and programs for reducing stigma. Both Leprosy and HIV/AIDS are public health problems and both are highly stigmatised diseases. AIDS is even referred to as 'the present-day leprosy' (as cited by barrett, 2005). the difference between leprosy and HIV/AIDs is that leprosy is regarded a neglected disease whereas HIV/AIDS has a lot of attention and a lot of funding available. The review reveals that the development of the stigmatising process and impact of stigma is similar in leprosy, HIV/AIDS & TB. Stigma affects interpersonal relationships, marriage, education, employment, mobility, participation in social gatherings and access to treatment and care and public health programmes.

### Psychological Problems encountered by People with Hansen's disease

As the people affected with this disease are rejected by the local community and family members, they are forced to stay in ashrams, Mandir (Temples), and leprosy homes. As a result of these problems, patients with Hansen's disease are associated with a high risk of developing psychological disorders. The prevalence of psychological disorders among these patients is higher than that among the general population. Scott (2006) argued that leprosy strongly influences the behaviours of people affected by leprosy. The disease can affect a patient's manners for the rest of their life. The high rate of suicidal attempts highlights the patients' concept of the psychological disorder as a result of leprosy. A variety of emotions are intensely experienced by leprosy sufferers. Grief appears to be the first and most general reaction that leprosy sufferers show after a diagnosis of leprosy. In some cases the morbidity becomes chronic and the incidence of psychiatric disorders is therefore indicated. Segregation and deprivation of the usual privileges of home environments lead to anxiety. They seem to have weak egos and lack independence in feeling, thinking and action. As a result of defeat and unsuccessful coping with new situations, they often withdraw. On the whole, these patients lack ego integration and poor adjustment abilities (Scott, 2006, pp41). Depression is the most common psychological disorder among these patients. Some of the major emotional

problems which leprosy patients feels includes depression, shame, dependency and even aggressiveness. Leprosy can affect the mentality of its victims by lowering their self-esteem, confidence and their dignity. These findings are consistent with several studies. Kufman et al (1986) demonstrated that depression is a very common reaction to loss of parts of the body or loss of body function such as appearance of deformity. (Menberu et al., 2001) also contribute idea which supports the above finding. In that work it was stated that, saddest of all, even people affected by the disease will believe many of the myths about leprosy as a result suffer from low self-esteem. Loneliness is a major psychological problem which people living with leprosy encounter. Dennis (1987), contended that, loneliness may expose persons to trauma. Consequently, those persons may get in post-traumatic problem unless they get appropriate counselling and support. In addition, due to either their loneliness or stigma attached to the disease, peoples with leprosy have high risk to be exposed to mental health and committing suicide. Leprosy affected people are hiding themselves from other people. They mostly tend to develop a sense of being secret. Similarly (Menberu et al., 2001) stated that one should not be surprised if people affected by leprosy continued to hide their condition from employers, colleagues and others, since they know that the consequence of its discovery would be worse.

#### ROLE OF COUNSELLING IN LEPROSY

Counselling is an integral and very important part of leprosy care and health services delivered in hospital, where leprosy affected individual and family is counselled in "holistic care"-because of high grade of social stigma, negative perception of disease, poor awareness and knowledge, poor self, social acceptance, poor psychological coping, poor socioeconomically condition counselling care is more necessary and important. In a highly stigmatised disease such as leprosy, the barriers placed by family members and society on those affected puts undue psychological burdens that must be freely discussed during clientcentred counselling. Counselling may be predominantly psychological, but the substantive part of the patient's social deprivation and marginalisation can be measured. Motivational Counselling sessions help people who need reconstructive surgery to have a clear idea of the process and possible outcome of surgery, giving them the option of making their own decision, and helping them to cope with fear, and choose the options which suit them. It is a paradox that when the country has declared elimination of leprosy, many of its vast population are still ignorant of the basic facts about the disease and the availability of treatment through all the general health services; many continue to believe in archaic ideas on the causation of leprosy and its consequences. Counselling services can therefore be seen as a powerful person to person educational tool to eradicate stigma and its practice. It seems that even patients with no visible disabilities require in-depth leprosy education, which covers cause of disease, how it is spread, regularity of treatment, side effects of drugs, disadvantages of irregularity, and encouragement to patients to visit the hospital as soon as any problems arise. They must be offered supportive counselling to cope with the fear and anxiety of getting additional complications. Any therapy needs to be appropriate to the condition being treated and counselling is no exception. It is a professional discipline and the counselling approaches to different categories of leprosy patients vary, especially when they

are facing extreme participation restrictions. Leprosy is a biosocial- psychological disease and requires multiple interventions of which counselling may perhaps be considered crucial in encouraging and empowering those affected to follow medical advice. Follow-up counselling sessions with this group of patients is needed to assess whether patients have accepted the reality of their disease, since a large number of patients have difficulty in overcoming age-old misconceptions about the cause of leprosy. The follow-up counselling session is also very necessary to re-examine their coping skills and perception about the disease.

### **CONCLUSION**

It can be concluded that the adverse effect of leprosy on both the victim and the society is very huge. Although, leprosy is a bio medical problem it also accompany other psycho social and economic problems which require a holistic approach to address it. Besides, the study was also able to reveal that the psychosocial and economic problems of leprosy have got a devastating effect on the wellbeing of the patients in a much higher degree than its physical effects. Stigma against leprosy patients affects all aspects of leprosy control (Bainson and Van Den Borne, 1998). Interventions aimed at solving the problem of stigma in leprosy are unlikely to succeed unless the various dimensions of the disease that influence the process of stigmatisation are understood. The need for self-acceptance, social acceptance and People with leprosy views their life and the way in which they conceptualized the disease is decisive factors for their levels of mental health. The intensity of emotions experienced by leprosy sufferers immediately after diagnosis underscores how important it is to have support immediately available. The support systems should include patients, families and relatives, employers, medical doctors and hospital staff to meet psychosocial needs of leprosy patients. Community acceptances are the major solutions to cope up with the psychosocial and economic challenges faced by people affected by leprosy. There is a substantial need for providing comprehensive psychiatric care to the patient afflicted with Hansen's disease. Social stigma has a significant role in inducement of psychological disorders in patients with Hansen's disease. Depression and anxiety disorders were predominantly detected in these patients. Early detection and treatment of psychiatric disorders among these patients is a powerful psychotherapeutic measure. Leprosy eradication is a long-term activity. The role of mental health professionals is important in tackling psychosocial issues related to Hansen's disease. Psychosocial assistance and support to the affected population of this disease will be helpful in eradication of this disease. This requires a national-level mass campaign of health education for the general public. The general public should be made aware that Hansen's disease is not a genetic disorder, it is 100% curable, and the patients need social support. A better coordination between all healthcare partners like dermatologists, psychiatrists, Neurologists & healthcare workers will settle all the issues and help in achieving the eradication goals. Integrated healthcare strategy will be beneficial to these patients. Health education is the most important measure in tackling this health problem. Physical and socioeconomic rehabilitation is worthwhile in restoring self worth and status in the community and helps patients to find employment. The importance of knowing that there are similarities is to

see if there is common ground in using appropriate interventions in order to reduce Stigma & Discrimination in Leprosy, HIV/AIDS & TB. Acceptance by the family and community of the condition of the leprosy affected person or the PLWHA can be a help to the affected person in the process of overcoming stigma. However, from personal experience it does not seem to be enough. Acceptance by the individual of his or her condition is necessary as well. The mind seems to be a powerful tool and negative thoughts dwelt on can have a destructive effect on the outlook of life of that person. The findings of the comparison stigma related to leprosy and HIV/AIDS show more similarities than differences. The beliefs of common causes, the involvement of the supernatural, judgement, misconceptions and religious teachings still prevail in both diseases.

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