13 Stigma in Leprosy

13.1 Introduction

Leprosy is a disease, which still strikes fear in the society as a mutilating, disfiguring, contagious and incurable disease. Leprosy has been a highly stigmatizing disease for centuries because of the horrifying nature of the physical disfigurement and no cure being available until the 20th century.

No disease has been more closely associated with stigma than leprosy, and it has become a metaphor for stigma. When the family or community knows that a person has leprosy he/she suffers economic and social losses, as well as participation restrictions in the community. Stigma attached to leprosy leads to loss of employment even before manual labour becomes more difficult due to disability that often results from late or no treatment. It also leads to exclusion from society, causing physical and emotional distress.

Even to this day, when leprosy is completely curable with MDT (multi drug therapy); beliefs like leprosy is a divine curse, a punishment of the past sins and results of immoral sexual behaviour are still prevalent. These beliefs reinforce the image of the ‘leprosy affected person’ as being physically and morally unclean, to be blamed for contracting the disease for their own fault and therefore to be ostracized. The repulsive physical image, the fear of infection and the belief that it is incurable are the root causes of the inhuman treatment that is often faced by those affected with leprosy.

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that 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. Leprosy affects many problems like avoidance, negligence, separation, torture and less respect in society etc. because of which they hide their disease.

Although denial may relieve the anxiety that follows from stigma, but with denial a treatable condition remains untreated and progresses and even reaches a stage when it is no more treatable, to cause unavoidable suffering.
13.2 Types of stigma

- **Felt stigma** refers in particular to the negative attitudes of the community felt or perceived by those with a stigmatized condition.

- **Internalized (or self-) stigma** refers the way people feel, who are (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 do anything”) and sometimes feelings of guilt or self-blame related to the stigmatized condition (“It is probably my own fault that I have developed leprosy”).

- **Enacted stigma** denotes actual occurrences discrimination (e.g. divorce, denying someone access to public transport) or negative behavior (e.g. gossiping).

- **Institutional stigma**: Stigma or discrimination which is part of institutional arrangements or policies. This would include separate clinic arrangements for people affected by leprosy, insufficient arrangements for confidentiality, laws sanctioning divorce or social exclusion on the basis of a health condition. Man-made barriers (e.g. buildings without elevators, sidewalks without ramps) in the environment may also be seen as part of the same category, as it restricts participation of people with disability and requires higher level advocacy for interventions.

13.3 Determinants of stigma

Lack of knowledge, negative attitudes, perceived fear of infection and blame & shame are the main determinants of stigma. Community attitudes are part of a cultural belief and value system. Attitudes are powerful determinant of stigma. A better understanding of what attitudes are and how they can be modified will help us fight against stigma.

**Fear** is a major driving force of stigma. People fear mainly two things: *deformity and social exclusion*, or more generally, the *negative social consequences* of leprosy. The latter would include diminished marriage prospects for children or other relatives and reduced earning capacity.

Fear can be deeply ingrained and may be associated with the *risk of transmission of the disease* or with the notion of perceived ‘impurity’ of the person affected. Fear to touch a person affected by leprosy is often seen even in doctors and other health workers who are not used to working with leprosy.
Causes of Stigma

**Physical dimension:** Appearance of patient with deformity, shabby look, foul smelling ulcers are the main reasons of stigma. Even members of the family are not willing to sit or speak with them.

**Threat of communicability:** people are afraid of being contracting the disease along with foul smell of the ulcers and the shabby look of the leprosy patients and rejection from the community.

**Threat of social avoidance:** Even those who have overcome the above causes may not establish contact with leprosy patients due to threat of avoidance, separation and negligence by society faced due to many strong traditional customs of the community.

**Self-stigma:** The patients with patches generally hide their disease due to fear of ostracism and create self-stigma. Patients may leave their villages without being abandoned either from their family or society.

**Uniform education:** Lack of actual knowledge and a feeling of untouchability about leprosy is the main cause of stigma and instead of universal messages IEC need to address specific needs of the communities to reduce stigma.

Leprosy Associated Stigma & Discrimination

If one becomes ill he would go to a doctor. Once he gets better, he would expect to get on with life as usual. But it’s not that easy for people who suffer from illnesses like Leprosy. Often, they suffer from persistent rejections and exclusions by ill-informed members of the community. Some people are even denied loans, health insurance and jobs because of their disease. Consequently, these people lose their self-confidence and may develop further anxiety or debilitating depression besides the physical and other problems being faced by them. Behaviour by the society sometimes becomes so unbearable that the affected person may even take their own lives.

The impact of leprosy stigma explains some paradoxical preferences in the utilization of health services. Although the availability of nearby health facilities is usually considered an indication of their accessibility and responsiveness to needs, concerns about disclosure of the condition may make nearby health services for leprosy too close for comfort.
13.4 The approach to reduce stigma

Even today people have misconceptions about the disease. They still think that leprosy is easily transmitted through touch; cure of the disease is not possible by the available treatment and deformities usually follow.

Till now, people were the passive recipient of the services and health functionaries used to inform the people about the cause of the disease, its symptoms and treatment to motivate them to seek treatment. IEC accomplishes the task of information, education and communication, but even a two-way communication between the health provider/educator and patient/or community is not enough. Mere information and education, to all and sundry about the signs and symptoms of leprosy and its curability, shall not work. It is imperative to break the barrier between persons affected by leprosy and the rest of the society, by appealing to peoples’ emotions and their ability to empathise with those they feared and shunned.

Strategy to reduce stigma must involve active participation between all three ie affected people, health care provider/educator and the community based on sense of human dignity, equality and acceptance of leprosy affected persons by the community. Health educator need to act as teacher and not preachers. The content of the information should be changed from frightening images of people disabled with leprosy to positive images of healthy cured persons sharing their experiences about the curability of leprosy and participating in the development of the community.

13.5 Suggested stigma & discrimination reduction strategies:

13.5.1 Inter-mixing of patients and public (community participation)

Integration of leprosy services to General Health Services: Since long leprosy has been treated in specialized institutions. Integration of services for leprosy affected persons to general health care system at all levels and their treatment by health care functionaries without discrimination will sensitize community.

Women mobilization: Females of the self help groups and head of the family can be sensitized about the disease and their services can be utilized for generation of awareness in villages to reduce stigma.

Old Leprosy affected Peoples’ association usually old age people face more stigmas due to economic dependence than others. These patients can be groomed as Peer Educators and used to disseminate the information on leprosy among other members, and also reporting the cases to Primary Health Centres. For this they could be given some kind of honorarium, which would act as an incentive for such people to come forward and support the community.
Complaint mechanism will help the leprosy affected persons to register or lodge a complaint through a toll free number in case of discrimination at the workplace, family or society level. Besides the use of IVRS (interactive voice recognition system) it will help people to acquire information on leprosy using this toll free number.

Awareness within the victims Some healing therapies for leprosy affected persons shall aid these patients to build positive vibes and regain their lost confidence. These classes could be organized by the NGOs, CBOs in collaboration with other local level functionaries and govt. departments.

Village level meetings: village leaders must be sensitized to allow LAP in different meetings and discuss issues related to leprosy and needs of the leprosy affected persons.

Health camps in the village where leprosy patients as well as others are treated together and the villagers could observe the normal behaviour of the doctor with the patient.

Cultural program can be presented for leprosy awareness through regional folk arts

Common feast be organized during any local fare where leprosy affected people can be involved to provide certain facilities to the people.

Public Garden where community people come for enjoyment will be maintained under the charge of leprosy patients to take care of it.

13.5.2 Awareness Generation

Sensitization of the media persons, so that they write positive about leprosy affected persons, service providers

Motivate the youth to come forward and educate the community about leprosy. Scouts and Guide, NYK volunteers, NCC cadets can take the lead role.

Sensitizing school children: Lessons related to leprosy in the text books of school, questions related to disease in the quizzes, easy competition, debates generate awareness in the school children and massages also propagate to general community.

Inviting budding writers to write positive and motivational stories on leprosy

Collaboration with the Department of Social Justice & Empowerment to help Leprosy affected persons get equal opportunities

Peer group counselling - Training five or six volunteers within the community and educating them on various issues of leprosy, who in turn will educate the entire community. Advocacy of old age persons, religious leaders and motivating them to carry forward the message to other members of the community in the informal manner.

Advertisement through local newspapers, posters, wall writing: Propagating the concept of Community Newspaper, among community members. Highlighting activities related to welfare of leprosy affected persons, their meetings or other activities and their achievements. This would give sense of achievement and ownership to leprosy affected persons.
Through **community radio** listening followed by discussions shall help to dispel myths and misconceptions

Street plays, documentaries, puppet shows on leprosy during local festivals to establish practical example of mixing

Group discussion especially with the women folk to motivate them for self reporting and provide correct knowledge about leprosy

Other new approaches may include people’s participation in the development process. The new approach uses services as education tool and involves community to generate public awareness and disseminate the message that fear of leprosy is ill founded, a mere contact with leprosy affected person does not pass the disease. Different approaches that can be used are (i) **Residential camps** in which the community see patients and service providers living and eating together and can see services providers cleaning patients’ wounds and ulcers, massaging and exercising their disabled hands and feet – thus making physical contact non-threatening. Patients are taught self-care practices. People share their experiences and learn from experience of each other. (ii) **Skin care camps** can be organized so that people can see and learn the signs and symptoms of leprosy and also how to distinguish them from other disease. Hence, a holistic approach of combining education, training and treatment may provide dignity to the leprosy affected person and change the perceptions of the community.