Stigma & Discrimination in leprosy

I. Introduction

Leprosy is a disease, which strikes fear in the society as a 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.

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 and even in distant islands.

Even after segregation, the societies and the Governments made discrimination to the persons affected by leprosy. A number of discriminatory laws were framed against such persons. At present, the situation has changed to a great extent. Now, leprosy is curable and patient can live in their home during treatment. Because of early treatment, deformities and disabilities have reduced. Many discriminatory laws have been repealed all over the world. Yet, there is discrimination against the person affected by leprosy, which need to be removed from the Public mind, so that these persons can lead normal life like any other human being.

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 by leprosy.

II. Stigma and its Types:

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. 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.

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 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 do anything") and feeling 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 of discrimination (e.g. divorce, denying someone’s access to public transport) or negative behaviour (e.g. gossiping).

**Institutional stigma**: Stigma or discrimination which is part of institutional arrangements or policies. This includes separate clinic arrangements for people affected by leprosy, insufficient arrangements for confidentiality, laws sanctioning divorce or social exclusion on the basis of the disease. Man-made barriers (e.g. buildings without elevators, sidewalks without ramps) may also be seen as part of the same category, as it restricts participation of people with disability.

### III. Determinants of stigma

(i) **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

(ii) **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. Community attitudes are part of a cultural belief and value system. Change in experience provides opportunity to bring change in attitude.

(iii) **Fear**: Fear is a major driving force of stigma. People fear mainly two things: deformity and social exclusion. Social exclusion includes diminished marriage prospects for children or other relatives and reduced earning capacity. 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.

(iv) **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.

### IV. Discrimination

Discrimination is the treatment of an individual or group with partiality or prejudice. Discrimination is often defined in terms of human rights and entitlements in various spheres,
including healthcare, employment, the legal system, social welfare, and reproductive and family life.

**Stigmatization and discrimination: Sigma and discrimination are linked.** Stigmatization reflects an attitude, but discrimination is an act or behaviour. Discrimination is a way of expressing stigmatizing thoughts, either on purpose or inadvertently. Stigmatized individuals may suffer discrimination and human rights violations. Stigmatizing thoughts can lead a person to act or behave in a way that denies services or entitlements available for other persons.

V. Intervention strategies

Stigma associated with leprosy is deep rooted, evolved through centuries of misconceptions and myths. **The process of achieving the acceptance of the leprosy patients in the community along with social status culturally acceptable in the absence of disease/illness should be treated as stigma reduction.** The strategy to reduce stigma in leprosy have to be mainly through:

**Spreading awareness:** Spread the demystifying messages and its interpretations, mainly regarding nature of disease, its cause, disease not being hereditary, role of immunity in occurrence of leprosy, availability of treatment and so on. However, 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 people’s emotions and their ability to empathize with those they feared and shunned.

Interventions for reducing stigma may be required at five levels – Viz. intrapersonal, interpersonal, community, organizational/institutional and governmental level. Stigma reduction programs should use a combination of approaches. Promising interventions are empowerment, counselling, contact with affected persons and education.

Following steps may help in this regard –

1. **Developing understandings & concepts based on scientific knowledge:** Although most people have some understanding of Leprosy, many lack in-depth or accurate knowledge about Leprosy. For example, many do not understand that leprosy cannot spread through ulcers in insensitive limbs of PAL. Involvement of experts from Medical College and research organization like JALMA (ICMR) should be useful.

2. **Preventing iatrogenic stigma:** Non discriminatory behaviour of health workers/medical officers while examining and treating e.g. dressing the ulcers and counselling can help in preventing stigma. Integration of leprosy services into general health care and practicing ‘no isolation –no discrimination’ policy in wards or OPDs, should be strictly followed.

3. **Involving communities/societies:** Strategies like Community counselling, group meetings and discussions using live case stories, incidences, involving treated leprosy affected persons in discussion, developing “self care groups”. Involvement of community in treatment provisions & Community Based Rehabilitation (CBR); based
on sense of human dignity, equality and acceptance of leprosy affected persons by the community and active participations between all three i.e. affected people, Health care provider/educator and the community may be used to reduce stigma

VI. Suggested line of action under NLEP

1. The National Rural Health Mission carries out IEC for various health related activities including leprosy. The State and District Programme Officers should coordinate with the respective NRHM IEC cell to incorporate leprosy in all the communication strategies under NRHM.

2. Develop strategy with the involvement of the following six groups of persons as partners to fight stigma against person affected with leprosy

   a. Civil societies: It is crucial to identify the political and the prestige structures and work through their leadership to create a climate conducive to bring in changes in the mindset of all people. Proper advocacy efforts to involve the civic society at large will be useful only if action is taken at all levels i.e. National, State, District and Local.

   b. Social activist: A large number of national and International NGOs work in the country and support PAL by providing curative and rehabilitative services. They also work to remove stigma. Partnership with these organizations, other organizations like Bharat Scouts and Guides, Gayatri Pariwar, Faith Based Organization (religious groups) and many others, engaged for the upliftment of the persons affected by leprosy will be invaluable.

   Involvement of celebrities like Actors, Artist, Musicians, sport persons; involved in social upliftment for spreading the messages through them may be very effective.

   c. Health service providers:
      - Demonstration of non discriminatory behaviour by all the Health service providers whether in the Govt. or outside
      - Involvement of practitioners of other system of medicines in spreading awareness.
      - Involvement of not only Dermatologists but other specialists like Physicians, Surgeons, Orthopedicians, Plastic Surgeons, Physiotherapists, Microbiologists, community medicine specialists etc in the Medical Colleges / District Hospitals is also very important.
      - Hospital managers and superintendents can support sigma reduction by making the hospital systems work without identifying the persons affected by leprosy as a separate group to deal with.

   d. Community / Opinion Leader: Opinion leaders can help by supporting and transforming community activities for support of PAL through case detection and referral, ensuring regularity of treatment by the patients, their socio-economic rehabilitation and accepting a cured leprosy in the society.
e. Corporate sector: can be contacted to generate and provide jobs and trades especially suited to or useful for leprosy patients like Smithy, Garment making, Carpenter and Crafts and allow them to work from their home

f. Media:
   - Media persons are directly involved in spreading awareness. Continuous advocacy by media can play a positive role. Sensitization of media personnel and writers, folk artists will help in spreading positive massages about disease. Advocacy through media is essential on continuous basis.
   - State level media coordination committees can be of great help in planning activities in the state.

3. Utilise Village Health and Sanitation Committee Meeting on “Village Health Day” to spread specific messages about leprosy through some of the experts for change in behaviour.

4. Develop and use effective, attractive and impressive communication of destigmatizing messages through different Media agencies.

5. During “Health Mela”, organize ‘care and concern camp’ with triologue and dialogues with the aim of combining services (Diagnosis, POD care) with BCC. Such camps organized jointly by community and health department with the purpose of demonstrating in discriminatory behaviour and zeroing distances along with providing services and educating people have been found to give strong impact.

6. Women mobilization: Females of the self help groups may be sensitized about the disease and their services can be utilized to generate awareness in villages to reduce stigma

7. Prepare and implement non-discriminatory behaviour guidelines for service providers which include institutions and individuals. Separate leprosy clinic room in PHC/CHC/SDH/District Hospital closed down immediately.

8. Empower the people affected by leprosy to over come discrimination by supporting ‘self care group’ in leprosy colonies. Involve the “Lok Doots” appointed by the National forum of persons affected by leprosy, wherever needed.

9. “Sasakawa India Leprosy Foundation” has a number of schemes to support the persons affected by leprosy and their children. Coordinate with the Executive Director, SILF, 228, Jor Bagh, New Delhi-110003, ph (011) 42403160, website www.silf.in, and support such initiatives.

These are only a few suggested lines of actions. The programme officers at State/Districts may feel free to work out and implement measures to reduce stigma against leprosy and remove discrimination against person affected by leprosy.
VII Key Messages:

1. **Human Rights issue**: All human beings are born free and equal in dignity and rights. This also includes persons affected by leprosy (PAL). Any legal, social & economic discrimination against PAL is violation of human rights.

2. **Early reporting to health centre for diagnosis & treatment**: Undetected adults with leprosy, transmit disease to children and adolescent. Therefore, the community should encourage early reporting to Health centre in case of any suspicion of leprosy.

3. **Use of words like ‘Leper’**: Words like ‘Leper’ or ‘Kodhi’ are used to define people by their disease, which are very humiliating to the affected persons. Such words must be eliminated from vocabulary, and education for this should begin from the school level. The Lepers Act 1898 was repealed by the courts in 1983; therefore use of such terms is also unlawful.

4. **Self Respect**: Persons affected by leprosy should be encouraged to overcome their shame and sense of helplessness and take a proactive role in preventing and solving their Physical, Social, Economic and Psychological problems.

5. **PAL helping other PAL**: Persons affected by the leprosy can provide effective support to the programme in the fight against stigma and discrimination, if asked for to help as Counselors, Teachers, Spokespersons and Lobbyists.

6. **Positive Slogans : Use of positive slogans like**
   (i) No deformity among new cases (Not Prevention of Deformity)
   (ii) Cure without the need for care (Not care after cure)
   (iii) Detect early, give MDT and prevent need for rehabilitation (Not community based rehabilitation)

7. **Caution to prevent**: Never start treatment for leprosy unless the diagnosis is confirmed – thus one can prevent pushing a person and family to the world of stigma and discrimination.

8. **Educator not preacher**: Provide useful Health education but do not try to preach.

9. **Cause of the disease**: Leprosy is caused by a Bacteria “Mycobacterium Leprae” and not because of any past sin or curse.

10. **Spread of the disease**: Untreated leprosy patients are the only known source for M. leprae. It is transmitted from a leprosy affected to a susceptible person via mainly the respiratory tract (droplet infection). The major sites from which bacilli escape from the body of an infectious patient are the nose and mouth. Nose appears to be the major port of entry of the bacilli. Leprosy is not spread by skin contact.