LEPROSY AND STIGMA
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Leprosy is the oldest scourge of mankind and still present in many parts of the world as a public health problem. It continues to remain an enigma. In spite of enormous progress in medicine and social sciences in recent years, leprosy is still situated in a twilight zone between science and myths. Discovery of Mycobacterium Leprae by Hanson in 1873 transformed the belief of scientific community about the disease. However, this disease strikes false fear in the societies as mutilating, disfiguring, contagious and incurable disease. Though it is not the disease of poor, it affects them to a too much greater extent because of their socioeconomic vulnerability.¹

Significant decline in the leprosy has been observed globally due to international, national and regional initiatives. For the first time in 1997 the number of registered cases globally was less than 1 million and it come to 0.5 million and 113 countries had attained the leprosy elimination goal by December 2003 (i.e. prevalence of disease of less than 1 case per 10,000).² The leprosy elimination strategy enabled the mobilization of significant resources and political commitment and it is one of the few infectious diseases to meet the strict criteria of elimination i.e. (a) untreated, infected human beings are the source of infection; [b] protocol and simple diagnostic tools are available; [c] Multi Drug Therapy (MDT) is an effective intervention to interrupt its transmission; [d] Under natural condition incident cases make of only a small fraction of the prevalence pool. Below a certain level of prevalence any resurgence of the disease is very unlikely. [e] Unlike tuberculosis, the leprosy does not appear to be adversely affected by HIV infection.³ However, incubation period of the disease is long and variable. Earlier a case of leprosy was diagnosed by eliciting cardinal signs of leprosy through systematic clinical (and whenever possible bacteriological) examination.⁴ Leprosy can be diagnosed on clinical signs alone.⁵ Government of India launched National Leprosy Control Programme in 1955 based on dapsone monotherapy. However, recommendations of WHO study groups in 1982 to initiate MDT had been a significant advancement. Due to the strong political will in the country National Leprosy Eradication Programme was launched in 1983. In consonance of world health assembly resolution in 1991 to eliminate leprosy at global level by year 2000, World Bank supported project I (1993-2000) & II (2001-2004) in India. At present programme is running through the funds of Govt of India and technical support from WHO as well as International Federation of Anti Leprosy association (ILEP) organization.⁶

National Health Policy⁷ (2002) set the goal of leprosy elimination as the public health problem (Prevalence rate of <1 case per 10,000 population) at national level by December 2005. Prevalence rate of 57.6/10,000 in 1981, 0.74/10,000 in March 2006 and 0.72/10,000 by the end of March 2009 clearly reflect significant decline in the disease following MDT. By the end of March 2009, 0.89 lakh cases were on record and 1.34 lakh new cases were detected during 2008-2009. Of the 1.34 lakh new cases detected during the year, 48% were MB cases, 10.1% child cases, 35.2% female cases and 2.8% were visible deformity cases. Only 3 states/UTs viz Bihar, Chhattisgarh and Dadra and Nagar Haveli are yet to achieve elimination⁸.

As far as leprosy is concerned, reduction of prevalence is not sufficient as the social consequence on the life of the patient is often severe and persists even after successful medical therapy

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It affects the peripheral nerves, patient losses sensation by and large in their hands, feet and eyes if not properly cared for injuries to those insensitive parts may lead to disfigurement. This is the main consequence of disease which leads to stigma and discrimination against person affected with leprosy.

The disease has remained through the ages a living death to the patient. It is considered as disfigured face, mutilated hands and discharging ulcer in feet. It is responsible for untold human misery mainly because of the disability it produces, which in turn renders the person unable to be a productive member of the society. These deformities/ disabilities bring upon the social prejudice which is perhaps more crippling than physical deformity. The disability causes a variety of handicaps and forcing some of them to be partially alienated from society (dehabilitation); and in the end a few may end up as destitute.

Leprosy was conceived of as a punishment for sin. The specific sins associated with leprosy varied somewhat overtime. In the early medieval period, leprosy was most often associated with heresy, but later sin was most likely to be worldliness and the punishment of a living death and removal from the world in its peculiar way to fit the perceived crime. 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. These beliefs reinforce the image of the “leper” as being physically and mentally unclean to be blamed for contracting the disease 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 after met out of those who have leprosy.

Leprosy as a disease brings misery to the patient and the family members also overreact when they come to know that one of them is a leprosy patient. Hence some of the patients do not reveal the disease even to their family members for the fear of rejection. Ideas of the contemporary society are in no way different from they were nearly 100 years ago. One third of leprosy patients were left by their spouses.

Leprosy remains one of the foremost causes of crippling deformities responsible for much of the social stigma and social ostracization of the patient. So long as the deformity, disability factor persists, so long as leprosy affected patients keep becoming more and more deformed disabled and dehabilitated, the stigma factor will continue.

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. 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.

The gradual decline in the number of registered patients needing MDT in the last few years has focused the attention towards the problem of disability caused by leprosy. Without the disability producing potential leprosy would have not got attention it gets. It affects schooling of children and attendance of leprosy patients at social and religious functions. 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. 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.
In medieval times, leprosy patients lived apart from healthy people around temples or shrines and they begged mercy to passers-by. In Tokyo and other places of the world there are museums which explain the nature of leprosy and the history of leprosy problems, for the eradication of leprosy stigma.

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.

It is difficult to analyse the traumatic experiences to which leprosy patients are subjected, and the tremendous changes that take place not only in the body but also in the mind when he is first told that he is suffering from leprosy. Because of fear of ill treatment by the society his initial response is to hide not only the disease but also the treatment. Myths regarding leprosy affect health seeking behaviour particularly early detection and treatment.

As soon as the society knows that a peculiar person is suffering from leprosy, the process of out casting starts due to poisonous effect made on society by many notions held by people about the disease.

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.

Reluctance on the part of doctors to join leprosy programme is quite common. It is considered as punishment posting and those who joined were stigmatised by their PEERS. Homeopaths are a hurdle in the success of NLEP. Leprosy workers are not only most disinterested in their work but also exhibit stigma towards the disease. Resistant staff and not the resistant patients is the major obstacle in the success of NLEP. Lack of belief or confidence in conventional medicine which often conflicts with the fact usually leads to patient seeking primary treatment from local healers. It is known fact that the delayed response in getting medical treatment for leprosy causes permanent physical deformities in the patient and gives an unhygienic picture that forces fellow people to look at the leprosy patient with hatred. A person tries to put up a brave face by challenging the society. He tries in vain, to postpone social death by postponing treatment.

Knowledge of community members about the disease has a strong bearing on their attitude towards leprosy patients. People having knowledge about leprosy has more positive attitude than general public. Stigma is hard to define and measure, being a complex reality made up as it is from a mixture of belief, attitudes and behaviors. Stigma has been defined as a blaming and ‘othering’ response, a way of thinking that helps people justify or deal with their fear of the disease. It ‘brands’ or ‘marks’ people as being undesirably different. To stigmatise people is to see them as unacceptable and of less value because of a feature or a quality they have, and to blame them for it.

It has following features:

a) There is a problem which initiates a certain reaction;
b) Those who feel threatened identify a group or individual to be targeted;
c) Those who feel threatened assign stigma to this individual or group and

d) Those who fee threatened then develop appropriate stigmatizing response.

It is expressed in terms of rejection, isolation, mocking comments and rude behavior.

Variants of stigma are: (a) Self-stigma –Believe & internalize negative attitudes, reactions & actions from others and fail to accept themselves as well as blame / ‘over-blame’ themselves (b) Stigma by association (c) Stigma by looks / appearance / type of occupation and (d) Societal Stigma

Thus leprosy stigma has been universal, has been present in all parts where leprosy was present. It effects are as follows;

- Persons living with leprosy feeling isolated, rejected, condemned, forgotten, useless.
- Kicked out of family, house, work, rented accommodation, organization, etc.
- Drop-out from school (resulting from peer pressure – insults, teasing, ridicule etc).
- Depression, suicide and alcoholism.

High level of self stigmatization was observed in leprosy patients when the programme was of vertical nature. In the event of lepra reaction (type-1 & type-2) peoples’ faith in modern system declines significantly. Perceptible decline in disability has taken place in old cases and even the new cases with disabilities after treatment do not appear in the leprosy case list. However, such deletion is not done from the mind of the patient and societal list.

Even in the present time people with leprosy have to leave their villages or socially isolated. However, stigma of the disease is seem to be already on decline worldwide in the following areas and several processes have contributed to this phenomenon:

- Cure: MDT can cure infected people who are coming back to their normal life
- Deformities and disabilities: They are becoming rare and rare
- Contagiousness : 95% of the humanity is naturally resistance to the disease and with the treatment patient has little chance of transmitting it which has made great impact on people who are dealing with it like family members and professional workers
- Segregation: Most of the leper are treated in integrated medical system and gaining self confidence to openly reveal their diagnosis and to speak out.
- Public Education: changing the name from ‘leper’ to ‘Hansen’s disease’, new translation of bible have helped to reduce some of the religious significance of leprosy by substituting “skin disease” for the word “leprosy” in the text.

Reduction of stigma of leprosy has to be done in partnership to the community and the patient. Following measures can have a positive effect on stigma:

[A] Legislative approach: Architectural correction is needed in the legal instruments to protect the right & dignity of leprosy patients.

[B] Service approach:

- Focus on following key elements of final push for leprosy elimination:
  - Integration of leprosy services into the general health services to improve access to treatment.
  - Capacity building to enable general health care staff to diagnose and treat leprosy.
  - Improve logistic to ensure adequate stocks of MDT at health centres.
  - Change society perception of leprosy and motivate people to seek timely treatment.
- Ensure high cure rate through flexible and patient friendly drug delivery system
- Simplify monitoring to keep track of progress towards elimination.

Special status of leprosy as complicated feared disease should be removed and it should be ensured that it is treated as just another standard curable disease. The newer accompanied MDT approach ensures that patients receive a full course of treatment. It has been adopted because someone close to or important to the patient assumes responsibility for helping him or her to complete a full course of treatment.

- Involvement of NGOs in provision of services in difficult areas is a desired task
- Training of health care workers to be more sensitive and empathetic to leprosy patient’s concern. They must be skilled for early deduction and management of leprosy patient and identification and referral of those with complications.
- Ensuring provisions of to reconstructive surgery and creating awareness about this can have a significant impact on functional status of individual.
- Counseling services are of utmost importance. This helps leprosy patients to cope with their disease and avoid self stigmatization and empower them to face discrimination.
- Adoption of preventive practices and training of leprosy patients may help to prevent further disability and deformity.
- Physical and socio economic rehabilitation is worth while in restoring self worth and status in the community and helps them to find employment. Extended support and rehabilitation services should be provided to patients and their families.

Educational approach:

It is crucial to change the negative perception of leprosy and encourage patients to come forward for treatment as soon as they note a suspicious skin patch. An effective and attractive campaign should motivate:

- People with skin lesions- to seek timely diagnosis and treatment;
- Health workers- to “think leprosy” when examining patients with skin problems;
- Community leaders- to fight against discrimination;
- Community members- to accept leprosy as a simple curable disease and encourage people to seek and comply with treatment;
- Decision-makers- to give their support for elimination and to make leprosy services readily accessible.

The attitude of health professionals can influence how patients and communities perceive leprosy. Educational efforts should be directed towards patients, families, PEER and community members (viz school children, youth, community influencers) and health professions. Empowerment of persons with leprosy is key to success in reducing stigma and raising their self esteem. Educating the leaders and community influencers may affect their decision and allow appropriate information to filter down. Media can play a significant role in changing the image of leprosy.

All religious leaders promote messages of love, humanity, kindness, companion, truthfulness etc. Many religions have a social wing to support marginalized section of the community by means of orphanages, charitable dispensaries, hospitals, educational institutions etc. Thus religious leaders a potential force and religious places can be a platform to bring a social change.

Empowerment of the persons with leprosy, physical and socioeconomic rehabilitation, and positive attitude of health professionals can contribute significantly in the reduction of stigma due to leprosy.

Govt of India is committed towards reduction in stigma and discrimination against leprosy patients and following programme components clearly reflect this view points.
Decentralized integrated leprosy services through general health care system.

Capacity building of all general health services functionaries.

Intensified Information, education and communication initiatives.

Prevention of disability and medical rehabilitation and

Intensified monitoring and supervision.

In addition to 36 NGOs, 27 Government institutions have been strengthened for providing reconstructive surgery services to disable persons with leprosy for correction of their disability.

In urban areas there is lack of functional community based health infrastructure and therefore in addition to high risk rural blocks urban areas have been given the benefits of urban leprosy awareness campaign. Urban leprosy awareness programme is initiated in 422 urban slums units with the assistance of Govt. of India.

For behaviour change following initiatives have been taken.

- 4 video spots on IEC
- Leprosy free India campaign since 03.01.2008.
- Mass media campaign- on DD, Aaj Tak, Zee News, Etv
- Independent evaluation of IEC activities.

At present new case detection rate is the main indicator for programme monitoring and is being calculated on monthly basis by the states as guidelines.

Treatment Completion Rate (TCR) obtained by cohort analysis is another indicator for the programme. Simplified information system has been developed for programme management and several other independent evaluation systems have been done besides routine programme monitoring. WHO is making significant contribution to the programme by giving financial and technical support along with provision of anti leprosy drugs to the country free of cost with the assistance from NOVARTIS. These initiatives have great potential for leprosy elimination on the basis of epidemiological indicators. However for elimination of the disease through societal lens require several other social actions and calls for more operational and behavioural research.

In summary, more holistic multi disciplinary and multi-component programmes are needed to address the stigma with interventions targeting individual, interpersonal health system, community and policy level. Understanding of determinants of stigma and process of stigmatization is an essential step towards developing effective intervention and validated stigma scale should be developed to assess and monitor the effectiveness of the programme and the programme approach should be based on psychosocial, cultural and behavioural modules.

In context of leprosy Dr. David Heymann has rightly remarked "the challenges of determination and dedication of joining hands and not letting to go until the goal of ensuring that no further lives are devastated by this disease is achieved" and "we are striving to make treatment readily available, a simultaneous priority must be to create a positive environment in which leprosy is seen in the same light as any other curable disease". All the techniques at our disposal must be deployed to make communities demand their right to live in a world without leprosy. We need people who show initiatives and who are not afraid to come forward with new ideas; individuals who wish to be active partners in this global effort.
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