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DISCRIMINATION AGAINST PERSONS AFFLICTED WITH LEPROSY AS A VIOLATION OF THEIR INTERNATIONAL HUMAN RIGHTS

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Abstract

Leprosy is a chronic but curable disease that causes skin lesion and nerve damage. Leprosy in India stood eliminated as public health problem as the number of occurrence went down to one per ten thousand cases, but in 2017, it made a comeback and several new cases were detected. It's easily the most misunderstood disease in India. Victims of Leprosy are constantly discriminated against, both socially and legally. There are as many as 119 laws that discriminate against people afflicted with leprosy. The general notion of the disease is still plagued by misconceptions people held before it was incurable. The purpose of conducting the study was to bring in forefront the situation of people suffering from leprosy and their families and the discrimination they face in day today life. This study was carried out by naturalistic observation of a Leper colony in India; additional secondary data has analysed to carry out this research. It's been observed that the society is not educated about the disease and lack of awareness poses to be a major roadblock in ensuring them an equal status in the society. Through the course of this study, it was realised that, though, there have been few progressive steps, like repeal of Lepers Act, 1898 and amendments in certain discrimination personal laws, but India still has a long way to go to ensure them basic human rights through policy changes and, by sensitisation of public about the particulars of the disease.

Keywords

Leprosy, Legal Discrimination, Social Injustice, Human Rights Violation

1. Introduction

The World Health Organisation declared leprosy officially eliminated as a public health problem in India in 2005, but the disease is still widespread in poverty stricken regions and social and legal bigotry have kept patients hidden and untreated. This declaration slowed down the door-to-door visits by the organisation to identify hidden cases. A passive detection phase that relied on people coming forward of their own accord for treatment proved to be a huge failure due to the stigma attached to the disease. As opposed to being eliminated, Leprosy is rather making a comeback. As of the year 2017, 135485 new cases of leprosy were detected half of which had already reached an advance stage of the disease due to deferred diagnosis. (Oommen, 2018) 57% of worlds' leprosy affected persons live in India. (Rastogi, 2019)

With this study, the researchers' intent is to bring in forefront the plight of patients suffering from leprosy as a reason of discriminatory laws and the social stigma attached to it. There are as many as 119 laws that single out people diagnosed with leprosy, directly or indirectly. Even after the repeal of 1898 Lepers act, India still has a long way to go in preventing discrimination against people contracted with Leprosy. There are laws that prevent them from contesting for local body elections, obtaining a driving licence or travelling in trains. They have to pay double than normal premium for insurance policies and several marriage laws make contracting leprosy a ground for divorce.

The study is conducted in one of the 1000 estimated Lepers colonies in India that patients are confined into far from main settlement areas, once they contract Leprosy. This lifelong banishment in itself is a blatant violation of their human rights, let alone other discriminatory practices.

- Research Methodology- This course will be conducted via interaction analysis after interviewing patients suffering from leprosy, by naturalistic observational analysis of leper colonies and by analysis of the existing primary and secondary data.
- Objective- The objectives include to highlight the social discrimination faces by leprosy afflicted persons, to analyse the discriminatory laws prevalent in India and to bring in forefront the challenges faced by persons afflicted by leprosy.

- Scope- The scope of study is restricted to analysing the discrimination against persons afflicted with leprosy, both legal and social.
- Sources of data- Both primary and secondary data have been used to carry out the study. Interview of people suffering from leprosy and their families, observation of the living conditions in leprosy colony are the source of primary data. News reports, Law commission reports and various scholarly articles have also been referred to during the course of this study.
- Chapterisation- This study has been divided to 5. The first part deals with the history relating to leprosy and discrimination that people afflicted with leprosy have been facing in India. The second part states out a comprehensive list of all laws and rules still in force in India, which discriminate people afflicted with leprosy. The third part mentions the international conventions India is a signatory of and the violations of these conventions in the country. The fourth part deals with the social stigma attached to the disease and the social discrimination people suffering from leprosy and their families are subjected to. In the last part of this study, there are suggestions and necessary steps that the government needs to take to ensure a discrimination free environment to persons suffering from leprosy.

2. History of Leprosy and Discrimination of Person Afflicted with Leprosy in India

Leprosy strikes any individual mind as a crippling, disfiguring, deadly disease that is incurable. There is no other disease with as much stigma attached as is leprosy. The spread and the cause of the disease are highly misinterpreted and mythical especially in a culture like India's. The bacteria is transferred mainly from the respiratory tract, it escapes the body of a person afflicted with leprosy mainly from their nose or mouth and not by skin contact.

2.1 During Ancient India

Leprosy is easily the most misunderstood and stigmatized disease in India. The reason for this is the long standing history in India, where the misconceptions about the disease were inscribed in ancient legal authoritative texts like Manusmriti and Sushruta Samhita. These Sanskrit treatises not only describe Leprosy as highly infectious and hereditary but also propagated segregation of patients into confined territories and deny them right to marry or inheritance. The Laws prohibited contact with those affected by leprosy and punished those who married into their families, effectively ostracizing those with the disease for their past sins. (Buhler, 1886) So even though the old believes and myths surrounding the disease have been

busted, the deep rooted beliefs in religious texts, as erroneous as they may be, have closed the minds of people to new facts and discoveries. Moreover, the Higher Judiciary in the country, in certain instances during early 20th century, has affirmed these erroneous beliefs by relying on ancient texts that disallow right of inheritance to a person with Leprosy, to give its judgements. (*Karali Charan Pal v. Ashutosh Nandi*, 1923)

2.2 During Colonial Period

During the British reign in India, formation of health policy for the natives was rarely a matter of concern. The health of indigenous people was peripheral, except when vital interests were threatened. (Ubrugn, 2019) As leprosy was not deemed a threat by the Government of India, it was resistant to pressures for greater intervention; Leprosy in India achieved visibility in the second half of the nineteenth century, largely due to its greater visibility internationally. (Kakar, 1996) Following the international wake of events, the colonial government was motivated to delve into the issue of policy formation with regards to Leprosy. Incidents over a period of 30 years, from 1870 to 1900, lead to the enactment of an act, which governed the fate of people with Leprosy in India. Three major incidents lead to an increasing support for arguments favouring segregation of people with Leprosy. During the 1872, the first leprosy census took place, which estimated that there were 99,073 persons suffering from leprosy in British India. (Abraham, 1889) The ration of prevalence of 54 cases/10,000 population and approximately 1% received organizational support, renewing the cries for segregation to facilitate delivery of care. (Pandya, 2004) Next, Hansen identified *Mycobacterium leprae* in 1873 and postulated it as the etiologic, transmissible agent of leprosy. (Kakar, 1996) Third, Father Damien, the Belgian missionary priest in Hawaii, contracted leprosy and died in 1889, proving its contagiousness (Jacob, 2008). These events led to the popular consideration of leprosy as a widespread contagious disease requiring containment. In response, a Leprosy Commission was established to investigate. The commission's report in 1891 concluded that “the amount of contagion which exists is so small that it may be disregarded”. (Jacob, 2008) But under increasing pressure from England and within India, the Government, disregarding the findings of the commission, enacted the Leprosy Act of 1898.

The object of the act was medical treatment and segregation of people afflicted with Leprosy. The act gave the right to police officers to arrest in prison a pauper leper. (Lepers Act, 1898) Any person who did not have ostensible means of subsistence or was found begging would be taken up in custody and after hearing would be sent to Lepers Asylum. (Lepers Act, 1898) The act also empowered the state government, by official notification, to prohibit people

afflicted with leprosy into trades such as making and selling any food, drug, drinks and clothes intended for human use or drive, conductor ride in any public transport etc. (Lepers Act, 1898) They were also not allowed to access public wells or tanks, if the state government passed a regulation for the same. Moreover, any person also who employs Leprosy patients for above mentioned trade or calling was punished with monetary penalty. (Lepers Act, 1898) Hence, this law mainly affected the poor because those who were self-sufficient were not obligated to be isolated or seek medical treatment, compulsorily. Since then, Leprosy patients were treated as a different class in themselves and subjected to inhuman treatment and discriminatory laws until very recently in 2016, when Lepers Act, 1898 was repealed.

2.3 Post-Independence

The National Leprosy Control Programme (NLCP) was started in 1955 as a part of the First Five Year Plan. NLCP was based on Dapsone domiciliary treatment through vertical units implementing survey, education and treatment activities and leprosy control work started in full swing. (Desikan, 2012) NLCP was able to achieve astounding success through careful planning and systematic work. In 1970s a definite cure was identified for Leprosy in form of Multi Drug Therapy (MDT) and came into wide use in 1982. (Nlepnicin, 2019) In 1982, following the recommendations of World Health Organisation, Government of India established a committee to look into arresting the disease in all cases of Leprosy. Consequently, NLCP was converted to National Leprosy Eradication Programme (NLEP) in 1983 that worked intensively towards elimination of Leprosy in India. NLEP was a centrally sponsored scheme of the Ministry of Health and Family Welfare, Government of India, provides free-of-cost MDT treatment to persons affected by leprosy through primary healthcare centres under the National Health Mission. Eradication programme was carried out in two different phases with the support of World Bank in 1993 and 2001. (Desikan 2012) In 2005, Leprosy was declared eliminated as a public Health concern. The cases of occurrence went down to less than one per 10,000 people in 2005. (WHO Report, 2006) After the declaration of elimination of this chronic and long incubating disease, the vertical leprosy control program was quickly integrated with the general health services.

3. Legal Discrimination against Person affected by Leprosy in India

Leprosy in India has been eliminated as a public health concern in 2005; MDT has been available free of cost since 1983 to Leprosy patients and a single dose of the medicine kills 99.9% Leprosy bacellius and renders infection non-contageous and non-virulent, according to the 256th Law Commission Report. Medicine developed but sadly the Law didn't. Till day,

there are more than 100 Central and State Laws in India, that discriminate against people inflicted with Leprosy either directly or indirectly. The 249th Law Commission Report recommended the Repeal of obsolete and discriminatory legislation, The Lepers Act, 1898. In 2016, the Legislature of the country repealed 'The Lepers Act'. It was welcomed step in the fight for equality for people with Leprosy but is only a small step in that direction. There are still over 119 discriminatory laws that continue to be a roadblock for ensuring basic human rights to Leprosy afflicted people. The mammoth number of 119 is enough to show the magnitude of problem prevailing in the country. And after repeated efforts from voluntary organisation, missions, trusts, NGO's and the media, the Government has turned a blind eye towards the problem. Even after the elaborate and detailed report on Leprosy recommending the repeal of such laws, in the 256th Law Commission Report titled "Eliminating Discrimination against Persons Affected by Leprosy", no steps have been taken to repeal any such laws. In 2017, Vidhi center for legal policy, an independent policy advisor group that worked with the Law Commission for the 256th report, filed a writ petition in the Supreme Court challenging the validity of these 119 acts on ground for violation of Article 14, 19 and 21 of the Constitution, that is- right to equality, right to life and freedoms guaranteed by the Indian Constitution. These 119 laws directly discriminate against people with leprosy; there are indirectly discriminating provisions from public health laws that apply to persons with infectious diseases generally without specifically mentioning leprosy. The following are the laws that require immediate repeal, amendment or modification to be amenable to the present day developments in leprosy.

3.1 Personal Laws

In India, there are different laws to govern marriage based on their religion and states. Hindu Marriage (High Court of Meghalaya) Rules 2013, Family Courts (Patna High Court) Rules, 2000, Jammu And Kashmir Dissolution of Muslim Marriages Act, 1999 and Jammu And Kashmir Hindu Marriage Act, 1980 makes incurable and virulent form of Leprosy a ground for divorce and in some cases nullity of marriage.

Jammu And Kashmir Hindu Adoptions and Maintenance Act, 1960 makes virulent form of leprosy a ground for the wife to live separately without forfeiting her right of maintenance from the husband. Under this section, person suffering from leprosy are embarked in the same category as husband treating his wife with cruelty, having another wife or concubine etc.

3.2. Beggary Laws

Beggary laws of Karnataka, Uttar Pradesh, Sikkim, Andhra Pradesh etc, single out beggars with leprosy and provide for their incarceration and segregation. Any person with leprosy found begging is detained or confined to leprosy asylums for an indefinite period. Children, who are wholly dependent on begging until the age of five and who have a parent suffering from Leprosy, are also liable to be detained under such Acts. People afflicted with leprosy are ordered to mental hospitals or a lepers asylum for the safety of the beggar or of others. Also, these acts use the term 'Leper' to refer to people afflicted with Leprosy.

3.3. Laws Relating to Representation in Religious Institutions and Professional Association

Laws like Jammu And Kashmir Shri Amarnath Ji Shrine Act, 2000, Hindu Religious Institutions and Charitable Endowments Act, 1997 and other such laws disqualify any person suffering contagious or a virulent form of leprosy to be a member of the committee or board to look after the management of these religious institutions. Tamil Nadu Hindu Religious and Charitable Endowments Act, 1959 under Section 25 lays out disqualification, suspension, removal or dismissal of any trustee who is suffering from leprosy.

Andhra Pradesh Medical Practitioners Registration Act, 1968 disqualifies a person from becoming a member of the council if he is a leper. Similar acts disqualify person with leprosy to be a member of Board of Director of the Federation or a committee of any society or board etc.

3.4. Laws Curtailing Freedom of Movement and Entry into Specific Areas

Laws regarding prison and Lepers Asylum state that a person afflicted with leprosy who have been accommodated in a leprosy asylum by sanctioning them a pass, shall not be allowed to move out of the without the sanction of person indicated in the pass.

Certain State acts restrict the entry of any person with leprosy into slaughterhouses. Kerala Places of Public Resort Rules, 1965 prohibits any person with leprosy inside licensed premise of the licensee as a mandatory condition to provide license. Travancore Cochin Public Health Act, 1955 under Section 82 disallows any person suffering from Leprosy to use public conveyance. And if they are to use it, they have to inform the driver or the conductor of such public conveyance. The driver can refuse, unless a sufficient amount is paid for disinfection, to convey person suffering from leprosy. Section 83 of the same act prohibits persons suffering from leprosy from attending school, college and taking out books or newspapers from public or circulating libraries. This act states out that there shall be 'Segregation Area' where person

suffering from leprosy are to be confined into. Madhya Pradesh Public Health Act, 1949 also provides for similar provisions as above.

Railway Act, 1989 deny the person afflicted with leprosy, right to travel in railway. Inland Steam Vessels (Madhya Pradesh) Rules, 1962 states no person suffering from leprosy shall be carried on board any vessel licensed to carry passengers unless an arrangement for their segregation is provided. Person afflicted with leprosy have to carry a certificate certifying him to be non-infective in order to travel on a metro railway as per the Metro Railways (Carriage and Ticket) Rules, 2014, Bangalore Metro Railway (Carriage and Ticket) Rules, 2011.

3.5. Laws Restraining Certain Professions

Several laws prohibit people with leprosy the grant of license for micro brewery other liquor related licenses such as Telangana Micro Brewery Rules, 2015. State laws also people with leprosy registering themselves for professions such as professional typist, deed writers, document writers, a pleader in court etc.

Andhra Pradesh Indian Liquor & Foreign Liquor Rules, 1970 strictly prohibits the employment of people suffering from leprosy for the purpose of sale, import, export or transport of Indian Liquor or Foreign Liquor within or without the licensed premises.

There are more such laws that prohibit the grant of license and employment of people with leprosy and in many of these laws and rules they have been placed in the same bucket as a person of unsound mind or lunatic.

Visva Bharati Act, 1951 provides that a teacher, other member of academic staff of the university can be removed from services if they suffer from leprosy. There are more than 30 university acts like Dravidian University Act, 1997, Karnataka Samskrita Vishwavidyalaya Act, 2009 etc that provide disqualification of membership of authorities from the university if they suffer from leprosy.

3.6. Laws Relating to Disqualification for Contesting Elections

The discriminatory provisions extend to even the election of a person to a civil post. Orissa Municipal Corporation Act, 2003 out rightly disqualify a candidate from contesting elections if he has been afflicted with leprosy. In Sikkim, Rajasthan, Madhya Pradesh, Odisha etc, they are disqualified from contesting election for Panchayat Raj and other local bodies like municipality.

4. International Conventions Relating to Leprosy and their Violation in India

Eleanor Roosevelt beautifully sums up what essential is protection of human rights when she says it begins in places so close to home that they cannot be seen on maps of the world. It begins from the protection of rights of the person in your neighbourhood, the people you personally come across on a street or in your college or anywhere. If the rights of these marginal numbers are not protected back at home, it's a vain to think about progress in the larger world. The previous section of the paper is a shocking representation of the condition of leprosy affected persons in India. India, being a signatory to the major human rights conventions, shows very little signs of their implementation when it comes to leprosy.

4.1. Elimination of Discrimination against Person Affected by Leprosy and their Family Members

The United Nations General Assembly unanimously adopted a Resolution on the Elimination of Discrimination against Persons affected by Leprosy on 21st December, 2010. It laid down principle and guidelines that need to be recognised and respected by the member states and reflected in their legal regime.

The principle unequivocally lays down that the member states should treat persons affected by leprosy and their family members as people with dignity and are entitled, on an equal basis with others, all fundamental freedoms laid down in Universal Declaration of Human Rights (UDHR), International Covenant on Economic, Social and Cultural Rights (ICESCR) and International Covenant on Civil and Political Rights (ICCPR).

The United Nations Convention on the Rights of Persons with Disabilities, 2007 (UNCRPD) also promotes and protects equal enjoyment of all human rights. Though not directly mentioned, the convention provides the framework for tackling the concerns of people with leprosy through equal opportunity measures, awareness programs and prohibitions against segregation and discrimination on the basis of their disability.

Despite adoption of the resolution on principles and guidelines in 2010, persons affected by leprosy continue to be discriminated in many ways. In fact, in India itself there are 119 legislations that discriminate against citizens on the grounds of leprosy.

Virulent and incurable form of leprosy still is a ground for divorce. The language used in the act indirectly supports the traditional misconceptions that leprosy is virulent and incurable. Words are copied from old books verbatim without acknowledging the change of many wrong ideas about the disease. If virulent is used to mean infectious, then other infectious

disease should also come under this act and leprosy shouldn't be singled out. And there is no such thing as incurable form after the introduction of MDT. Therefore, if the idea is protection of the healthy partner, then it is wholly misconceived. Leprosy is mildly infective and adults usually have immunity against them. This is why we usually do not find healthy spouse getting the disease from infective one. Even the doctors do not contract it from the patients. We ourselves come across them so often without realising it.

If looked from the other side the law is inhumane. A leprosy patient is more in need of help and support, both physically and mentally from his wife. If he is left at such a stage, it will also reinforce the idea in segregation and other people around him will be equally afraid to live with him. Hence, it not only violates human rights directly but also contributes to the stigma related to leprosy.

A patient is still refused a ticket by a railway official, and driving his or her own vehicle too is out of the question because of the laws prohibit the provision of license. If the disease is rendered non-infectious after the treatment, there is no reason why they should not be allowed train travel or driving public service vehicles.

Children affected by leprosy often find it difficult to seek admission in schools due to stigma. There are instances where persons affected by leprosy are denied admission to institutions providing vocational training, refused employment and denied health and life insurance.

On top of all this discrimination, leprosy affected person are forced to leave their houses by their family, especially the women after marriage by their in-laws, breaking all emotional, physical and economic ties with them. And then when it comes to living alone and earning a livelihood for themselves, law again places restrictions and prohibitions on employment of people with leprosy. There are already enough social stigmas attached to leprosy for law to be placing more restrictions. Even today, they find it difficult to be employed for menial substandard jobs because people still think of leprosy as an evil, infectious and maligned disease. Naturally, this will lead to rise in beggary. It's a vicious circle, they are denied proper education, then employment and when they resort to begging, they are forced into prisons or asylums for indefinite periods along with their children.

4.2. UDHR, ICCPR and ICESCR

Universal Declaration of Human Rights (UDHR) affirms basic rights and fundamental freedom are inherent to all human beings and that every individual has the right to a decent life. Yet, persons affected by leprosy continue to live in excluded /segregated institutions and

colonies their entire life. There are 850 leprosy colonies in India that stand as a testimony to the forced segregation practiced in the past. Segregation supplements the wrongly formed belief of people about leprosy. Then afflicted persons find it extremely difficult to integrate into the society again. Poverty and distances from big cities is a living reality in most of these segregated colonies. They have to travel long distances to access health care benefits, livelihood options etc. hence, many people resort to public transport, which is also highly constricted. Even the use of the term “Leper” in official documents is derogatory. The term also hampers the efforts for the inclusion of Persons affected by Leprosy into mainstream society and affects their sense of dignity as human beings. In the past, the victims were regarded as sinful and immoral persons, and leprosy was connected with sins committed in past life. In some of these laws, leprosy patients are put in the same basket as those “of unsound mind”. In certain instances, they are charged additional fee for disinfecting the public transport after they travel and in specific cases they were to show a certificate rendering their disease non-infectious every time they took a metro rail. More than discriminatory, it is humiliating for a person to be subject to such laws. It directly attacks the dignity of a person and human dignity is the main philosophical foundation of human rights. Such restrictions degrade the dignity of persons affected by leprosy and make them feel unwanted and ostracised. It damages the moral fabric of the society.

ICCPR that ensures basic rights such as those to contest for, and hold, civic posts continue to be violated under State Municipal and Panchayati Raj Acts. Even, most of the articles ICESCR remain unfulfilled and un-respected for. Its articles cover self-determination, economic and social and cultural rights, right to work and fair remuneration, protection of the family, adequate living standards, physical and mental health, education, participation in cultural life, and access to the benefits of scientific progress. Stigma associated with the disease has led to exclusion of affected persons in social and religious functions held in the communities. Women affected by leprosy continue to face multiple discriminatory practices in the community and within the family.

The provisions of the above mentioned conventions and regulations are enshrined in the Indian Constitution also, as Fundamental rights of citizen. Hence, the discriminatory, dehumanising and degrading laws and practices violate not only the conventions but the fundamental law of the land too. It violates Article 21 that is right to life, that includes right to live with dignity, Article 19 that ensures freedom of movement and freedom of occupation and Article 14, that provides for right to equality. In international human rights law, equality is

founded upon two complementary principles: non-discrimination and reasonable differentiation. The discriminatory provisions are not based on any reasonable differentiation as after the advancement of medicine Leprosy is curable and can become non-infectious. They are only based on traditional misconceptions. When it comes to reasonable restrictions under Article 19 also, the same reasoning that leprosy is curable renders the restriction void. As far as article 21 is concerned, Individuals possess basic human rights independently of any Constitution by reason of the basic fact that they are members of the human race. The expression “life” in Article 21 does not connote merely physical or animal existence. The right to life is given a purposeful meaning by including the right to live with human dignity. Hence, the impugned laws not only deny persons affected by leprosy their right to be treated equally as other, similarly situated persons, but also restrict such persons from exercising their fundamental freedoms and rights which are guaranteed to them under Part III of the Indian Constitution. Due to the denial of basic freedoms and rights, to which every citizen is entitled, it becomes very difficult for persons affected by leprosy to sustain themselves and contribute to their own well-being and that of society.

India has signed and ratified the UNCRPD, and is also a member of the UN General Assembly. Hence, Under Article 51 of the constitution of India, India has an obligation to uphold its international obligations and commitments and suitably change or repeal its laws in order to make them more amenable to the present-day needs of the Persons affected by Leprosy in light of the UN Resolution on the Elimination of Discrimination against Persons affected by Leprosy, that specifically calls on nations to abide by the Principles and Guidelines. It is not only an obligation but an urgent need as people afflicted with leprosy continue to face flagrant violations of their basic human rights every minute of the day and it is only when such discriminatory laws are repealed that the social stigma attached to leprosy will reduce.

5. Social Discrimination

“It is not just the government’s policy but people around us, in smaller villages, they stop talking to people like me, nobody gives out food even for money or gives us shelter. In fact, they forced my family to kick me out of the house because they feared they would contact it” said Sukhia, one of the oldest residents of the leper’s colony. She, like most women was kicked out of the house as soon as she was diagnosed with leprosy. “I left behind my kids and my family, my in-laws made me but I will be ever grateful to Almighty for He spared my kids and chose me to bear this disease.” said she. While working on the fields, Sukhia noticed boils on her palms. They were unresponsive to any touch, poking or piercing. On paying a visit to

the village doctor, she was further sent to the city doctor whose signature was the final declaration to this lifelong exile. She has grandchildren now who she has never seen. The family chooses to completely dissociate with her for if they didn't, no one would marry into the family. While most women were assigned banishment alone, men suffering from the disease moved into the colony with their whole family.

At the lepers' colony, it was a common sight to see patients and those unaffected by leprosy eating together, they even slept on the same beds, used each other's clothes and there were common vessels for everyone's use. "I am not at all scared of contacting the disease. I know that's not how it spreads. I have lived here all my life and so have the other children, no one ever got it. What's to worry?" said the 12 years old Muskaan whose grandfather moved in to the colony with the whole family several years ago. Almost 25% of the inhabitants at the leper's colony were families of the patients and were unaffected by the disease.

While stigma is a collective attitude, discrimination is a covert behaviour. The lack of awareness about the disease has consequences that go further than the legal system. People suffering from leprosy also suffer economic and social losses (participation restrictions) causing physical and emotional distress. The fear of infection, the belief that it is incurable and myths related to its contamination make the lives of lepers arduous. Patients contaminated by leprosy are each unemployed. The government offers pension to the senior citizens, a mere 300 INR each month. The insufficient fund forces them into beggary due to lack of job options. There is misconception that the disease is highly infectious or a genetic disorder that counts for irrational behaviour. The misconstruction of cause and spread of disease is such that children of parents affected by leprosy can marry only those who are either sufferers of the disease or have a similar family background. Apart from this absolutely ridiculous social injustice, as confirmed by Sukhia, lepers are even today considered untouchable. The cause for their condition is believed to be a result of their past sins and an outcome of their own doing.

6. Suggestion Relating to Necessary Steps to Curb the Discrimination

First and foremost, step that requires urgent addressing is the repeal or amendment, as necessary, of the impugned provisions to bring them in line with UN Resolution on the Elimination of Discrimination against Persons affected by Leprosy. These laws, acts, rules should be changed; the stigma of leprosy will disappear when they are abolished.

The Law commission undertook a study of amending/repealing discriminatory laws against people with Leprosy. It was published in 2015 as the 256th Law Commission Report titled "Eliminating Discrimination against Person Affected by Leprosy". It was a fairly

extensive study that dealt with the social and legal stigma attached to leprosy. The Report too recommended repeal/amendment of the discriminatory laws and acts. Additionally, it calls for affirmative action that promotes social inclusion of person affected by leprosy by adopting welfare measures in line with contemporary challenges. The law commission has drafted an independent bill titled “Eliminating Discrimination against Persons Affected by Leprosy Bill, 2015” (EDPAL Bill), if the bill is implemented it will solve a great deal of challenges that leprosy afflicted persons face.

The holistic approach is required in amelioration of the conditions of victims of leprosy. Persons afflicted by Leprosy face obstacles in not only in the legal front but also social, educational and economical fronts. Therefore, the situation has to be tackled from a host of different directions and the policies need to address the issues relating to health care, employment, education, social welfare, awareness and training about leprosy etc.

With concern to the social discrimination, awareness is the key. All the myths and misconceptions related to the cause and spread of the disease must be combated. This communication should be interpersonal, intrapersonal, government level and through communities and organisations. It is of utmost importance to spread scientific knowledge based concepts and understanding. Apart from this, the sufferers must be informed about the curability of the disease and the benefits of early diagnosis so that they can break free from the social pressures and come forward for their personal health. Undetected adults are the only confirmed source of the disease and that makes it even more important for them to come forward in case of any suspicion of leprosy. This can be enabled by preaching the actual cause of leprosy (microbacterium leprae) which is definitely not “past sins” so as to stop victim blaming and shame fastened to the disease.

Creating awareness regarding the cure and transmission of Leprosy can prove extremely helpful against the discrimination and stigma against Persons affected by Leprosy and their family members can be systematically curbed. This can be achieved by advertisement campaigns on television and movie theatres. They should be concessions for people undergoing treatment for hospitals, government institutions and private establishments travel and lodging during treatment. Economic empowerment is a crucial need that needs to be addressed. The Governments should look into providing employment quotas or alternative employment opportunities, where they are physically capable of being employed. Land rights and financial security should be ensured to persons living in leprosy colonies. Finally, the law should make

sure that they are not discriminated against by taking affirmative actions, prohibiting and form of discrimination in any institution and by providing them adequate basic amenities.

Sadly, neither the Central nor the State legislations have taken any step so far in implementation of the EDPAL Bill. Consequently, Vidhi centre for legal policy, an independent think tank has challenged these disputed discriminatory laws by way of a Public Interest Litigation in the Supreme Court in 2017. The decision of the court is pending. But there is still a long way to go for India to call itself an abider of Elimination of discrimination against person affected by Leprosy and their family members.

7. Conclusions

The history of leprosy in India offers insights into one of the world's most misunderstood diseases. While social stigma attached to leprosy continue to prevail, the laws still mirror blatant discrimination against leprosy afflicted person. There is also no medical basis for such restrictions and they are based on wrongful assumptions. Despite considerable progress made in the field of leprosy, old ideas about this disease still occupy the minds of the people, particularly of the makers of the laws. Many of these laws were written before the development of MDT. They have not been updated since and do not reflect the current understanding of leprosy. Though, it cannot be denied that there have been few developments in the right direction.

In the recent past, the legislature and judiciary have taken progressive steps towards ensuring equality to person with leprosy. In 2016, the Lepers Act, 1898 was repealed and in 2018, five personal laws including the Hindu Marriage Act, 1955, removing leprosy as a ground for divorce, were repealed. The judicial decision in *Bajal Basappa v. Keshava* case, struck down a law disqualifying persons affected by leprosy from voting in an election to a Municipal Council as violation of right to equality. In *Pankaj Sinha v. Union of India* and *Maharashtra State Road Transport Corporation v. Uttam Shatrughan Raserao* cases also, the Court held that stigmatisation affects human dignity and the basic concept of humanness and since Leprosy is now curable, persons suffering from the disease need to be treated and rehabilitated instead of being shunned. These are positive steps, but relatively insignificant from the point of view of addressing the situation of people suffering from leprosy.

It is surprising to note that a good number of the impugned discriminatory laws have been enacted post 2005, after Leprosy was declared eliminated as a public health problem and clearly, after the introduction of MDT. This clearly shows a lack of understanding about

leprosy and erroneous exercise of power by the rule making authorities. Besides, the recommendations of Law Commission in its 256th report have not been addressed and the 119 discriminatory laws still remain in force in the country. Neither the Central Government nor the State Governments have enacted the Eliminating Discrimination against Person Affect by Leprosy Bill proposed by the Law Commission. Furthermore, there are fresh challenges cropping up like the pension of Rs 300 to people afflicted with leprosy in leprosy colonies is proving insufficient and inadequate with the rise in prices of goods and commodities. Also due to physical deformities, leprosy affected citizens are unable to provide biometric verification leading to deprivation of benefits that government provides for vulnerable groups. The lack of ownership and title of land in leprosy colonies adds to their misery.

It is evident from the situation of people suffering from leprosy in India, that they not only have to deal with a painful, prolonged disease but also from emotionally crippling social situation like discrimination and loneliness. Too many people with leprosy remain trapped in a never-ending cycle of discrimination and disability. It is the lack of awareness about the rights of persons affected by leprosy and the complete information about leprosy that is the causes of stigma leading to discrimination. On the surface, discrimination is linked with old stigmas that still lead to segregation and human rights violations of people affected by leprosy. However, this stigma is only the tip of the iceberg in terms of why people continue to be denied their more basic human rights.

Here the study concentrates on the residents of one of the leprosy colonies. While a comparative study of other leprosy colonies in different cities of India would bring out an interesting perspective since India is a highly diverse country. Also, the cities in the same states are variedly developed in terms of infrastructure, education and various other factors. The comparison can plausibly throw light the factors that affect the intensity of discrimination that victims of leprosy face. This can give a better solution to the problem at hand.

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