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Leprosy in India: Current Issues and Prospects

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Abstract

Leprosy, an age-old chronic bacterial affliction in human civilization is caused by Mycobacterium leprae through long exposure of the respiratory system to airborne nasal droplets. It is derived from the Greek word 'leprós' meaning 'scaly', relating to the skin. Leprosy mainly affects the skin and peripheral nerves, which holds the risk of enduring and progressive visible deformities. Additionally, associated stigma bothers the leprosy patient through discrimination or exclusion, even after the completion of treatment. Leprosy patients with late diagnosis generally develop irreversible disfiguring complications. Late detection may result from poor knowledge, ignorance, unavailability of services, and stigma. This paper is a review of leprosy to understand the present situation in India in terms of burden, myths, stigmas, beliefs and attitudes of the community, Knowledge, Attitude, Practices (KAP) studies, programs, and initiatives by government in the Indian scenario. It also analyses to understand the disease perception and it was found that the majority of respondents possess little or no knowledge, and negative attitudes. Suitable recommendations have been devised to guide professionals in effectively planning and structuring solutions for the welfare of leprosy patients.

Keywords: ***Leprosy Affected Patients, WHO, Knowledge, Belief, Stigma, Attitude***

Introduction

Leprosy or Hansen's disease is a chronic infectious disease which is caused by *Mycobacterium leprae*. It mainly affects the skin, peripheral nerves, eyes, and the mucosal surface of the upper respiratory tract (WHO, 2014). The nerve damage upsets the autonomic, sensory, and motor nerve functioning ultimately causing disabilities if left untreated (Van't Noordende et al., 2019). Leprosy can occur at any given age but can be cured and early treatment turns away most disabilities.

Not just the physical consequences, leprosy-affected persons (LAP) deal with a heavy stigma that almost always accompanies it which may remain even after the completion of treatment. This adversely affects the quality of life of the patients and their families due to its impact on interpersonal relationships, employment, leisure, and social activities (Mankar et al., 2011). The exact transmission of the leprosy mechanism is yet to be confirmed but recently, the transmission of bacteria through chronic exposure of the respiratory system to airborne nasal droplets is believed to be true (Van't Noordende et al., 2019). Some possibilities even suggest transmission through insects(WHO, 2014).

Leprosy now mainly exists in tropical and subtropical climatic regions, barring any remarkable variation of occurrence in terms of geography and climate (Subramaniam, 2003). It is also more common in the developing and underdeveloped countries of the world, owing to factors like lack of healthy diet and healthcare facilities, insanitation. It is a highly contagious chronic disease with low morbidity due to its natural resistance among most individuals. Therefore, leprosy can never become an epidemic, owing to the true sense of the word (Subramaniam, 2003).

Regarding sex distribution, leprosy affects both sexes. However, in most countries, more males are affected than females, often in the ratio of 2:1. This prevalence is seen in diverse geographical areas like India, Hawaii, the Philippines, Cameroon, and Venezuela. However, it is not universal and in many other areas, particularly Africa, Japan, and Thailand there is an either equal occurrence of leprosy in both sexes or rarely even a higher prevalence among females(WHO, 2016b).

Controlling Leprosy: A Battle Against Stigma

Currently, leprosy is controlled through early detection and treatment. WHO has recommended preventive medication in the form of Single Dose Rifampicin (SDR) which works as post-exposure prophylaxis (PEP) for contacts of LAP which possibly decreases the risk of developing leprosy in them by 60% (Mieras et al., 2018).Additionally, the BCG vaccine offers ample protection against leprosy with its main target of tuberculosis.

Earlier persons afflicted by leprosy were ostracized by their families and community. Even though that has changed now, they are still chastised by the community and fail to receive support or empathy from others. The stigma stems mainly from incorrect knowledge about leprosy, the mystery surrounding its transmission, and its available treatment options("WHO Expert Committee on Leprosy. Fifth Report," 1977) (Singh et al., 2012).Paradoxically, after almost two decades of excellent treatment options, from MDT to remedies for associated reactions and ulcers, the majority of individuals still seem weakly motivated to seek timely treatment (Subramaniam, 2003).

Diagnosis and Treatment of Leprosy

Leprosy is easily observed and elicited by a health worker based on clinical signs and symptoms, rarely requiring a laboratory investigation to confirm the diagnosis. It involves hypo-pigmentation, skin lesions with loss of sensation, and skin smear positive for acid-fast bacilli prevailing in any individual occur(World Health Organization (WHO), 2019) (Richard et al., 2016).

Current and ongoing treatment for leprosy includes a regimen that combines two- three antibiotics including dapsone, rifampicin, and clofazimine. Since these are used together, it is called multidrug therapy (MDT) and has been recommended by WHO and used since 1981. The MDT treats an affected individual over a period of six months or twelve months for PB (Paucibacillary) and MB (Multibacillary) respectively. MDT successfully kills the pathogen. It is effective with minimal side effects and thus, widely accepted. The relapse rate is low with no drug-resistant organisms produced so far (Pattyn & Grillone, 2002) (Subramaniam, 2003).Some doctors recommend anti-inflammatory drugs including steroids like prednisone to subside any damage and pain to the nerves caused by leprosy. Another potent medication, thalidomide is occasionally prescribed to suppress the immune system to treat the skin nodules from leprosy.

Along with drug treatment, leprosy management includes a multi-disciplinary approach consisting of physical therapy and orthopedic care for the associated deformities, plus educational programs regarding leprosy for the patient, and community members so that social rehabilitation of the patients can happen (Subramaniam, 2003).

Methodology

This study used secondary data from various articles, review articles, and research papers from published National and International journals available on the internet, along with data and statistics provided by primary websites like the World Health Organization taking into account the global and Indian scenario of leprosy. The aggregation of this data was later analyzed.

Recent Trends in Leprosy Situation

Global Leprosy Situation and its Burden

The global and regional leprosy situation updates are published in the Weekly Epidemiological Record (WER) by the World Health Organization (WHO).

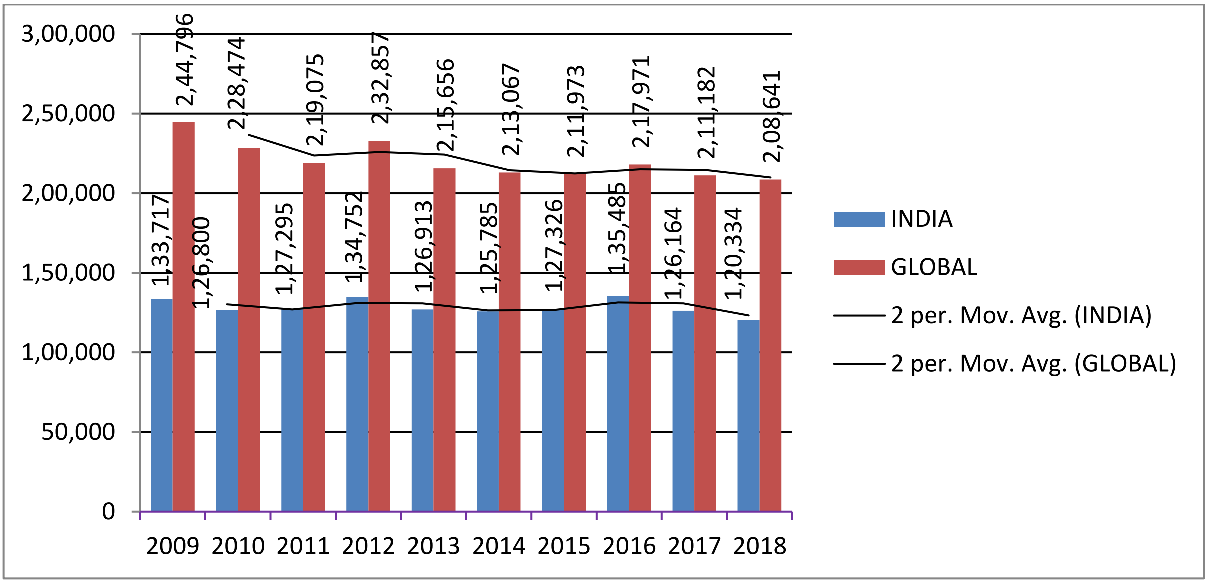
Controlling the increase of leprosy cases has significantly improved because of various national and sub-national campaigns in the endemic countries. Primary leprosy services along with effective collaborations and partnerships have helped in lowering the leprosy burden to a considerable amount (“Global Leprosy Situation, 2012”).

National programs for leprosy have adopted the Global Leprosy Strategy (2016-2020): Accelerating towards a leprosy-free world. The three pillars of this strategy are: to strengthen governmental ownership and partnerships, stop leprosy and associated complications, stop discrimination and promote inclusion (WHO, 2016a).The year 2018 is the mid-point in the implementation of the Global Leprosy strategy, and the data collected were analyzed to assess the progress that the countries made to reach their targets set for 2020.

Annual statistics for 2018 from 161 Member states and territories for leprosy were received. From 2009 to 2018, annual reports from WHO regions exhibited a trend of a slow decrease in new case detection by 15% during this decade. The SEAR reported 3.2% lesser cases in 2018 than in 2017, owing to a reduction in the cases reported by India, while other WHO regions had increased cases.

However, SEAR accounted for the major load of 71% of new global cases; where India and Indonesia contributed the highest. Brazil accounted for 93% of new leprosy cases In the AMR region. These countries together make up 79.6% of new cases worldwide from 2009 to 2018.

Graph 1: Trends in new cases detected in India and Global, 2009–2018



The graph shows the trend in new case detection (India and Global) from 2009 to 2018. Although the global trend seemed to decline almost steadily except for some increased spurts in between, India had a more fluctuating trend and contributed to 57.67% of the new cases globally, detected in 2018(World Health Organization, 2019).

Present Situation of Leprosy in India

The National Leprosy Elimination Program (NLEP) in India is a centrally sponsored health scheme launched by the Government of India under the Ministry of Health and Family Welfare. This is supported by WHO, and ILEP, among other organizations. Due to their rigorous and constant efforts, India witnessed a downfall in the national prevalence rate from 57.8/10,000 in 1983 to less than 1/10,000 in 2005, and further down to 0.66/10,000 in 2016 with the implementation of MDT, and achieved “elimination of leprosy as a public health problem”.

Besides achieving the national elimination goal by the end of 2005, India also successfully managed to eliminate leprosy at the state level in 34 out of 36 states and UTs by the end of March 2011-2012, leaving behind the state of Chhattisgarh and the UT of Dadra & Nagar Haveli. By March 2016 end, 551 (82.36%)out of 669 Indian districts had a prevalence of less than 1/10,000 which was the elimination goal of leprosy as a public health issue. 76 districts had prevalence between 1 and 2/10,000, 39 had prevalence between more than 2 and 5/10,000, while two had prevalence between 5 and 10/10,000 (Pn. Rao & Suneetha, 2018).

Even with these achievements, India continues to be responsible for 60% of global new cases reported annually. India is among the 22 “global priority countries” accounting for 95% of the global numbers, warranting sustained efforts to bring down leprosy cases.

The number of cases detected in 2016 was similar to those detected in 2007. A significant increase in cases in 2016 from 2015 can be attributed to the strategy of pioneering Leprosy Case Detection Campaign (LCDC) introduced under NLEP, which helped to bring forward 34,000 new cases in 2016 from very high endemic pockets, reporting 25% of annual new cases. From the total cases detected, almost half suffered from MB form of leprosy, and the child rate was approximately 8.7%, similar to the figures of the past year. Both these indicated the continued transmission of leprosy among the population. LCDC helped to increase the number of districts with aprevalence of more than 1/10,000 in the country, thereby proving the value of strategies that help in active case finding (Pn. Rao & Suneetha, 2018).

According to the annual reports of NLEP, the last 4 years have constantly displayed a prevalence of more than 1/10,000 population in four states and UTs, namely Odisha, Chhattisgarh, Delhi, and Lakshadweep), which had earlier achieved elimination formerly in 2011-2012. This became a matter of serious concern for NLEP. Moreover, the average national child leprosy rate reached about 9%, and the proportion of cases among children was more than 10% of new cases detected in eleven states and UTs, from which six states and UTs showed very high rates, ranging from 14% to 23%. Out of these, few even showed a high MB form of leprosy (Pn. Rao & Suneetha, 2018).

Review on KAP Regarding Leprosy in India

Almost every community has some culturally determined beliefs and misconceptions about leprosy that lead to an intense negative attitude toward the affected people. Several studies conducted in India have been reviewed to understand the general idea regarding leprosy.

A study in Maharashtra among cases and controls found that leprosy-affected patients(LAP) were more aware of leprosy in contrast to the control which can be attributed to the education provided along with the treatment (Mankar et al., 2011).

P. S. S. Rao & John’s study (2012) in urban slums of Kolkata revealed that the majority (93.8%) of the subjects had some knowledge about leprosy but only one-third were aware of the cause. Only some knew about the early signs and symptoms, and treatment while another similar study conducted in an urban slum of Telangana showed poor knowledge levels (Danturty, 2016).

A cross-sectional study among patients in western Rajasthan revealed that 51% of the subjects had zero knowledge of leprosy and almost half of them believed leprosy to be infectious. The majority (73.68%) were aware of the cause and knew that leprosy could be treated but was mostly unaware of the treatment duration (Handa et al., 2015).

A comparative study between high and low-prevalent districts of West Bengal found that patients from highly prevalent districts reported better knowledge levels, indicating that the place of residence and level of education directly influenced the knowledge score of the patients (Saha et al., 2015).Pal et al. studied healthcare providers of Assam and explored their current KAP and found that 90% were aware of the cause of leprosy, and 92.5% were aware of diagnosis, categorization, and treatment based on the category of leprosy. All of them knew MDT, and 80% had an idea about NLEP (Saha et al., 2015).A recent study on the basic KAP about leprosy was conducted in South Kerala among students of medical college. A semi-structured questionnaire revealed good knowledge levels(Philip et al., 2018).

Beliefs and Misconceptions Regarding Leprosy: Community Attitudes

Communities from around the world hold false beliefs and misconceptions about leprosy. Even after the advancement of medical science in effectively curing leprosy, these beliefs remain embedded in the minds of people, which nurture the negative attitudes and stigma attached to leprosy.

A study in the Fatehpur district of Northern India found high levels of stigma and fear, and a desire to maintain distance towards LAP since they apprehend leprosy transmission through touch. The main misconception regarding the cause of leprosy was blamed on an unhygienic and unclean environment. Another delusion is thought to be bad blood (Van't Noordende et al., 2019).Singh et al., 2012, in their study found that 64.9% of the subjects believed that leprosy was caused due to supernatural causes like karma, God's punishment, and sin.

Despite knowing that leprosy is curable and not contagious, the attitude of society remains mostly unchanged posing great difficulty for LAP. They suffer negative feelings like shame, guilt, or fear, and dread the social consequences of their condition. Van't Noordende et al., 2019, in their study in the Fatehpur district of Northern India found that maximum number of subjects (56%) preferred discretion about their condition. Few revealed that people refuse to visit their houses even after treatment. A minority (8%) isolated themselves from work or public gatherings. Community members avoid talking to, sitting with, or touching a LAP, and they are not invited to celebrations.

In a study conducted in the urban slums of Kolkata, it was seen that half the respondents felt that LAP should be treated separately from the general patients, however, they did not mind working with or visiting a LAP (Saha et al., 2015).Another study in Rajasthan found that about 39% of respondents feel pity upon seeing a leprosy patient, 11% feel afraid, and 3% feel disgusted when faced with a LAP. Almost 59% of subjects would not mind sitting next to LAP, and 39% would not be comfortable sharing food with a LAP. 43% of subjects were fine with their children playing with a LAP, and 47% stated that they will not let kin marry a LAP (Handa et al., 2015).

A study in the rural community of Tamil Nadu found negative prevailing attitudes among patients after contracting leprosy. It was reported that most family members (73%) did not share articles used by LAP. The majority of the family members thought that LAPs are employable. Around 45% of family members felt that a cured LAP could marry. The majority (90%) of LAP participated in social functions and more than half (64%) did not waver in eating meals beside others(Stephen et al., 2014).A comparative study conducted among high and low-prevalent districts of West Bengal showed that subjects from high-prevalence districts and younger age groups attributed better attitude levels (Saha et al., 2015).Danturty (2016) in their study discovered a negative attitudes accompanied by pity toward LAP. Subjects were willing to accept LAP belonging to their community instead of being an outsider. They were not comfortable sitting beside shaking hands, sharing food, working with, or housing with a leprosy patient. They would not accept a family member marrying a LAP, even after treatment.

Conclusion

The available literature indicate that although the leprosy burden has decreased significantly over the past decade, it cannot be ignored, and must remain on the health agenda, to sustain elimination where it is already achieved and increase efforts where the target is yet to be achieved.

Although the Global Leprosy Strategy has proved beneficial in bringing the global prevalence rate down almost steadily except for some increased spurts in between, India in 2018 showed a more fluctuating trend and contributed to 57.67% of the new cases globally. Nonetheless, with continued efforts by NLEP, it is expected that India will successfully tackle leprosy and achieve elimination by the next decade.

Most studies have shown inconsistency and deficiency in terms of knowledge among LAP and their family and even if the knowledge was adequate, the attitude and practice toward LAP were mostly unfavorable. Even after advances in the treatment of leprosy, and the global level of political commitment to reducing the leprosy burden, the social stigma usually felt by the LAP, is characterized by social exclusion, blame, rejection, and participation restriction. This leads LAP to conceal their status which results in delayed diagnosis and treatment. To further work on the existing programs to improve the situation of Leprosy following important interventions need to be aligned with the existing ones:

- Leprosy-related knowledge must be improved by educating the masses through various means like personal or group counseling, using audio-visual aid, practical visualization exercises via stereotype defeating LAP, and social marketing like mass media campaigns, school-based education, posters, and street plays.
- Deeply embedded beliefs often interfere with the attitudes of individuals even when they have sufficient knowledge. Sometimes, simply stating scientific facts is not enough. It becomes important to include the local community’s cultural beliefs, fears, and misconceptions rather than disapproving of them while providing health education. Health educators should find the right blend of traditional beliefs and the modern theory of medicine. Traditional beliefs like the effectiveness of Ayurveda treatment should not be overlooked but integrated into education for better results.

- Sensitization at the Panchayat level and gender-specific sessions could be further encouraged. A team of professionals including a health educator and policy maker should be recruited to gain expertise and tactfully use that in the interventions. They must consider physical and socioeconomic rehabilitation that would help to restore the self-esteem and standing of LAP in the community.
- Active surveys for leprosy case detection must be done instead of relying upon a self-reporting approach. The basic data obtained must be organized and computerized according to geographies, and the problem of confidentiality which affects the reporting practices data must be addressed.Rigorous research is needed on the holistic framework of cultural, behavioral, and psychosocial models and theories, and using multivariate statistics to identify important independent predictors of stigma and their relative importance. Cross-cultural studies will compare the factors leading to differing attitudes toward LAP in different cultures.More impact studies need to be done to evaluate the change. A validated stigma scale could prove beneficial to monitor the effectiveness of the programs. A periodic assessment of the quality of life of the LAP would help to better shape the policies and programs intended for leprosy welfare. Statistics on relapse would help to understand drug resistance.
- Continuous research and evaluation will also enhance deeper insights into community perception of one specific disease like leprosy and its correlation with other disease causation. A comprehensive understanding of health in the communities as well as their correlates with other diseases helps in improving the framework for health analysis and outcomes for a healthy India.

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