

Disabling Women Further: A Gendered Lens on the Leprosy Affected

Seema Baquer

Abstract

Against a brief background on the condition and current situation with regard to prevalence of leprosy in India, the author draws on existing research to highlight the gender-based issues in the life of women affected by leprosy. Having elucidated various dimensions of the problem, the author assesses the disability law, its provisions and its failings in catering to the rights of women affected by leprosy.

Author Profile

Seema Baquer, LLB, India & BCL, Oxford, is an Independent Consultant on cross-disability issues & Consultant with the Advocacy & Communication Domain of The Leprosy Mission Trust India (TLMTI).

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Background

Surrounded by myths, misconceptions and deep-seated fears, leprosy also known as Hansen's disease, remains poorly understood even today. Leprosy is mildly infectious disease caused by *Mycobacterium leprae* and is transmitted via air carrying fluid from the nose of a person with leprosy. It has long been associated with physical disfigurement and disablement as a result of nerve damage and loss of sensation.

Although a cure for leprosy was discovered in the early 1980s in the form of multi-drug therapy (MDT), the segregation and exclusion from society continues to be a reality for those affected by the disease. There are two main types of leprosy cases: paucibacillary (PB) leprosy cases and multibacillary (MB) leprosy cases. Both types of leprosy can be treated by MDT administered for varying lengths of time. Although leprosy is contagious in nature, it requires prolonged contact with an infected and untreated person to contract the infection. Untreated, leprosy leads to deformities because of which it is considered to be the leading cause of disabilities attributed to communicable diseases. Moreover, with the advent of MDT, a person is rendered non-contagious after the very first dose of the drug. As a result of this, there is no longer any reason to separate the person infected with leprosy from the community.

However, there is little awareness about leprosy, how it spreads, and how it can be treated. Consequently, people are unaware of the fact that even those cured of the disease may continue to develop deformities, disabilities, and ulcers due to irreversible nerve damage which cannot be cured by MDT. Thus, a negative perception and exclusionary socio-cultural response to leprosy and towards people infected with leprosy persists.

Additionally, the reaction to MDT during and after the treatment affects skin pigmentation leading to patchy skin, which can make the person receiving treatment 'stand out'. (Sarkar and Pradhan 2016) The physical changes as a result of the disease and in response to MDT has an impact on the lives, expectations, and self-worth of women far more than men. This has a negative impact on women's body image and makes women believe that they may no longer fulfill the roles of daughter, wife, and mother. The negative portrayals of leprosy in the media and the strong links between leprosy and ugliness further complicate the situation.

As per the data available on leprosy in India, there are approximately 10-12 million people affected by leprosy, to which roughly 1,30,000 people are added every year, as per the registered number of new reported cases under the National Leprosy Eradication Programme (NLEP) of the Government. Only a minuscule percentage of new cases comes from the nearly 750 leprosy colonies in India. The majority of new cases come from the general community, when people hide their disease and return to the community.

Although, India reached the WHO standard of elimination of leprosy as a public health problem in December 2005 (according to which less than 1 new case is detected in a

population of 10,000 in a year) there remain pockets in India, where leprosy is still endemic. India continues to contribute the highest number of new leprosy cases in the world and carried 63% of the global leprosy burden in 2017. (Ann Aerts, “The Modern Challenge of an Ancient Disease”, *Huffpost*, 19 April 2017; “Is leprosy disease of the past” n. d.)

Another misconception around leprosy is that it is the disease of the poor alone, as it affects those with low and compromised levels of immunity. This is something that has a negative impact on women and children in India.

Leprosy and Women

As per the latest data from NLEP, on an average, a woman is diagnosed with leprosy every ten minutes (“Is leprosy a disease of the past” n. d.) However, it must be remembered that not all of them may be suffering from deformities.

Various studies from India and around the world highlight the idea that gender plays a significant role in the lives of those affected by leprosy: it influences the social, emotional, and psychological ramifications of the disease. It would be pertinent to mention here that the majority of the studies reviewed for this paper focus on health.

In considering the gendered impact, the first issue revealed is the differential access to diagnosis. Global trends in the reporting of leprosy show a 2:1 gender disparity ratio (Price, 2017). Although detailed disaggregated data by sex is not collated under NLEP, in the overview of the data it can be seen that the ratio of females has generally been within the 1.5 to 1.85 for every male (<http://nlep.nic.in/data.html>, last accessed on 9th August 2018). However, due to the active Leprosy Case Detection Campaign (LCDC) by the government in the previous year, the latest report shows a better ratio of 1.35:1 (men = 70,621; women = 53,072) reporting with a noted increase of 8.74% in the reporting of female cases. However, in the State/Union territory-wise data in the latest report the ratio remains below the 2:1 ratio, coming close to it in some states. The only exceptions are Dadra & Nagar Haveli and Puducherry, where 51.56% and 60.61% are females, respectively (NLEP Annual Report 2016-17, Ministry of Health & Family Welfare, http://nlep.nic.in/pdf/Annual%20report_%202016-17_rev.pdf, last accessed on 8th August 2018)

There are significant gender differences in the behavior of reporting and seeking treatment. A study conducted in India and Pakistan showed that women are far less likely to self-report leprosy. They do, however, benefit from active case detection programs. The hesitation to self-report could be due to a variety of reasons including cultural barriers against the examination of women (especially unmarried females) and the risks of stigma especially where primary healthcare is provided by village housewives amongst others (Shale, 2000). In India, it can be assumed that there are a fair number of unreported cases especially of women and girls. Gender influences likelihood of detection of disease as women do not go in for diagnostic tests. Thus, reaffirming the fact that women’s agency in the decisions and actions to access healthcare for herself remains poor.

Studies have found where a woman faces inequality on account of her gender, she suffers a further burden with the discovery of leprosy symptoms. This also makes it difficult for her to access services, in cases where these services are available. A recent article drew a particular reference to India from an older paper titled ‘Gender differentials in the social impact of leprosy’ (Rao, S., Garole, V, Walawalkar, S., Khot, S., & Karandikar, N., 1996) and noted that they

“...found a clear gender disparate delay in initiating and continuing to administer formal treatment, observing that the low social status of women in India directly results in greater suffering for women. They reference extreme dependence and discrimination in every area of their lives as a defining characteristic of the poor situations in which women can find themselves.”(Price, 2017)

This obvious lack of autonomy is heightened in cases of leprosy. Women – on account of their role as daughter, sister, wife, daughter-in-law – have to rely on the decisions made by the male authority figures in their households to access healthcare. For most women, it is the male authority figure, in many cases the husband, who would decide when to seek medical intervention (John, Rao, & Das, 2010). In such a scenario, the woman would firstly have to disclose her symptoms to the family making her vulnerable to the possibility of being stigmatized, ostracized, and even deserted. The fear of discrimination is so high that women hide the signs and symptoms of leprosy until the disease starts to interfere with the performance of their daily chores or visible signs of it begin to appear. This leads to delayed diagnosis and the setting in of disabilities. A study conducted on 53 Indonesian women highlighted that there is a correlation between the concealment of the disease and the fear of anticipated stigma. Fear of stigma left the women with feelings of sadness, shame, low esteem and depression and ended up making them more vulnerable (Peters, Hofker, Van Brakel, Zweekhorst, Seda, Irwante, & Bunders, 2014). Field experience also shows that women are likely to avoid getting treatment until their children get married, especially if the children, specifically the girl children, are of marriageable age.

People affected by leprosy, especially those who face loss in sensation, require life-long medical care. Thus, diagnosis is merely the first step. Although MDT is provided free of cost in India, the long-term care of a person affected by leprosy would mean a large financial undertaking. This means that the persons affected with leprosy would also be financially dependent on their families. According to studies, women in developing countries like India are the last in their families to access healthcare because of their financial dependence on men (Sarkar & Pradhan, 2016).

Lack of employment opportunities or independent sources of income for women also adds to this dependence. A study in India had found that women affected by leprosy were likely to earn less money for the same amount of work as compared to other men with leprosy and women without leprosy. Figures from the study revealed that,

“... whilst leprosy patients in general had lower employment rates than control groups, females experienced greater employment problems than males, being 61 % less likely to be employed than controls, with male counterparts only 30% less likely. Those females

able to take work received 4 times less income annually than controls, whereas men earned only 1.7 times less. The area under study appears to affect rates of employment, and a separate study in a different area of India revealed 75% of male patients to be employed, with 49.5% of females finding work” (Shale, 2000)

Additionally, for those with severe deformities and complete loss of sensation in hands, finding employment becomes unlikely and for many, beggary remains as the sole option of sustenance.

Time is another challenging factor in accessing medical care. Repeated visits to the hospital, in-patient admissions, long waits at various points in the system, and regular follow-ups are time consuming activities that keep women out of the home. A study in India highlighted how women’s responsibilities within the home impede her ability to avail medical services (Price, 2017).

Taking time out for treatment is but one aspect of the struggle for women. The effects of untreated or delayed treatment of leprosy leads to difficulties in performing chores such as cooking, cleaning and lifting heavy objects. Additionally, if the woman patient is advised against standing for long hours in order to avoid pressure on the feet or told to use protective gear while cooking, she may find this difficult to adhere to if she is to discharge her household responsibilities efficiently. Studies have shown how these limitations in the performance of family roles (which many families and many women perceive as essential to their womanhood) can lead to emotional breakdown, a sense of guilt, and a lowering of status within the family. These challenges are compounded especially if there are other females in the household and the woman has a desire to leave the home which can cause economic hardship (Price, 2017; Shale, 2000).

Being prevented from completing their household tasks (for fear that the disease could spread) can lead to emotional challenges besides the anguish resulting from a confirmed diagnosis. The refusal of touch, especially of one’s own children is a related traumatic experience. This loss of intimacy for the woman is the worst form of isolation and rejection (Vlassoff, Khot, & Rao, 1996). Many continue to live under discrimination, segregation, abuse and neglect rather than face desertion. The likelihood of abuse is greater where the family finds it difficult to accept the medical condition (Price, 2017). These issues and the perceived fear of stigmatization, not only by the family but also by society, leads people to hide their condition from their extended families, friends and community. Yet, once discovered de-habilitation is a living reality for many with the segregation extending beyond death for some.

Women are more likely than men to face de-habilitation. A study showed that women are more likely to be forced into leaving their homes than men, showing that:

“68% of males chose to leave, but only 49% of women took this decision themselves; 31 % were made to go by their family, compared to 20% of males. Women who remain are more likely to encounter negative attitudes from their partners than men. Fear of deformity (63% of females, 49% of males), and future forceful de-habilitation, was a concern that led to females voluntarily leaving the household, despite similar rates

of actual deformity. Another factor in deciding to leave was to avoid prejudicing the chances of future marriage for their relatives, expressed by 35% of this cohort, and by patients in other studies” (Shale, 2000).

However, there is a fear that leprosy might have an impact on the chances of marriage. This fear is higher in relation to women and is one of the reasons for delayed diagnosis in younger women, as they hide the signs and symptoms of leprosy while they are of marriageable age (Shale, 2000).

Furthermore, unions from amongst people living in colonies show that women affected by leprosy are more likely to marry men affected by leprosy who are more disabled than themselves. During a study in the leprosy colony in India, “...one remarried leprosy affected woman explained, ‘Why would they take us if our hands were wasted? They have married our hands which cook and clean and sweep!’” (Vlassoff, Khot, & Rao, 1996).

The constraint on choice of partners has an impact on the children of people affected by leprosy as well, especially those living in leprosy colonies. A study stated that a male child of a person affected by leprosy said,

“We will marry one day to one of the girls in this community itself. So, there is no curiosity, no excitement. We know who are the probable matches, and they are few. ...But the situation of girls in our colony is worse... Their world remains very small within the bounds of this colony. And then we boys find them very boring as partners.”(Vlassoff, Khot, & Rao, 1996)

Moving from options of marriage to marital life, women with leprosy, much like most other women in the Indian context, have little sexual autonomy. Leprosy adds to the vulnerability: she might be rejected as a sexual partner on account of having leprosy, she might have to resign herself to her husband having extramarital sexual partners, and she might have no option but to accept a man with leprosy as her husband (van’t Noordende, A. T., Van Brakel, W. H., Bantsola, N., & Dhakal, K. P., 2016; Vlassoff et. al., 1996; Price, 2017; Shale, 2000)).

In a cultural context where the woman’s primary role is to be a wife and mother, having leprosy makes both tasks difficult, thus bringing into question the woman’s existence. As explained,

“leprosy and its reactions have a close connection to reduced immunity, thus the symptoms of both have a high chance of occurring during puberty and pregnancy. Due to the hormonal changes during this time, the first signs of leprosy may show, reactivation of the disease, and relapse in “cured” patients is likely to occur and particularly in the third trimester of pregnancy reactions may get triggered. The reactions can continue long into lactation (Sarkar & Pradhan, 2016).

According to Shale, “Both dapsone and rifampicin can occasionally cause hemolytic anemia, which may be of increased significance in already anemic, menstruating women and dapsone can affect folate metabolism, and in chronically undernourished patients, may be significant in the development of anemia.” (Shale, 2000)

In light of the above, the long-term effects of multiple pregnancies for a woman affected by leprosy in India, where majority of them are anemic and many malnourished would require further enquiry.

Various studies point to the absence of gender sensitive medical care available to women with leprosy. To check for leprosy, the body needs to be examined for patches. For the comfort of the patient, there is a need for privacy and for properly trained female medical practitioners at all levels (Price, 2017; John, et. al., 2010). There is an urgent need to focus on the gender dimension in the planning, rendering, monitoring and evaluation of health services and in raising awareness about leprosy. Keeping this in mind, the WHO in its Global Leprosy Strategy 2016-2020 has a special focus on women and children and on how to deliver to them quality services related to leprosy (http://www.searo.who.int/srilanka/areas/leprosy/global_leprosy_strategy_2016_2020.pdf, last accessed on 11th August 2018). ILEP has also included the need for a focus on women and disaggregated data by sex as well in its new strategy (ILEP Strategy 2016-2018, 'Achieving a world free from leprosy', <https://www.leprosy-information.org/files/ILEP%20Strategy%202016%20-%202018.pdf>, last accessed on 11th August 2018).

Field experience shows that women in leprosy colonies face the kind of patriarchy found in the broader society from which they were ostracized. These colonies are internally managed by a panchayat. However, a woman panchayat member would be rare. Subjugation coupled with the lack of autonomy and decision-making power for women is perceivable yet silently and unquestioningly accepted within these parallel worlds.

Leprosy, Law, Gender

The Rights of Persons with Disabilities Act, 2016 (RPD Act) includes leprosy-cured as a specified disability and in some of its provisions takes a gender perspective. Thus, the present law on disability is being examined to assess how it can respond to the issues discussed above.

Discrimination is a major barrier for women in accessing medical care, thus leading to wastage of crucial time. Because stigma is linked to the physical manifestation of the disease, discrimination begins long before the person is released from treatment and declared 'leprosy free'. However, the RPD Act as it stands today fails to cover this aspect. It selectively protects the rights of those who are diagnosed or have been cured, it leaves out the most vulnerable ones, those in hiding who are yet to be diagnosed and those under-going treatment.

This gap was understood by the 21st Law Commission of India, when it was approached to look into various discriminatory provisions in laws on the grounds of leprosy. Empathetic to the enormity of the problem and the reality of discrimination, it made specific recommendations for non-discriminatory provisions that would cover not only those affected by leprosy (including those yet to be diagnosed and those cured) but also the families of those affected by leprosy. It also highlighted the need for affirmative action (Law Commission of India, Report No. 256, 'Eliminating discrimination against persons affected by leprosy', April 2015). Although, projected as an anti-discriminatory legislation, the RPD Act falls short of truly being so by making an exception on grounds that "the impugned act or omission is a proportionate means of achieving a legitimate aim Section 3(3) of the RPD Act, 2016". Additionally, the lack of a

stringent mechanism of check in the application of this provision along-with the burden lying on the person with disability (PwD) makes it a more difficult terrain for women. The general lack of understanding about leprosy increases the probability of the misuse of this provision to keep people affected by leprosy out.

What is needed is to raise awareness about leprosy, its treatment, consequences and its social implications, so that discriminatory as well as self-stigmatizing attitudes can be addressed and eliminated. The section on awareness under the RPD Act amply covers the areas of inclusion, ability of PwDs to contribute to the workforce, sensitizing employers, co-workers and administrators amongst others (Section 39 of the RPD Act, 2016). For leprosy this task ought to be shared in coordination by both the Ministry of Social Justice and Empowerment (MSJE) and the Ministry of Health and Family Welfare (MHFW), which at present continue to work in silos. The MHFW is undertaking the task of raising awareness on leprosy through the Sapna Campaign to promote early detection but such efforts would require long-term financial commitment.

While a well-intentioned provision for healthcare (Section 25 of the RPD Act, 2016) is included, the challenge is to ensure its implementation especially in cases of leprosy, where early medical assistance is necessary to prevent the onset of deformities and disabilities. To make this provision a reality for women with leprosy, special action plans would have to be made in order to reach out to them. Women affected by leprosy and their families need intensive and regular counselling on the disease, on need for early detection and intervention, on long-term self-care and on possibilities of leprosy related complications during pregnancy and puberty. Efforts at counselling have shown an improvement in the completion of treatment and overall health outcomes with reduced chances of stigmatization (John, Rao, & Das, 2010).

Post the elimination of leprosy in India, the separate focused health program was merged into the general healthcare delivery system, which did not happen smoothly and effectively leading to a dire need to train medical and para-medical personnel on the medical and social aspects of leprosy, so that a gender sensitive delivery system could be ensured. Long-term programs for leprosy screening should also be built for areas that have faced natural disasters and conflict. Natural disasters and conflict lead to serious nutritional and immunity issues which could make the population susceptible to leprosy since the bacteria that causes it can incubate for up to a decade before it manifests as the disease (Shale, 2010). Moreover, the health-related provisions in the RPD Act fail to address the mental health needs of PwDs as an essential component of health services. This is a pre-requisite in cases of leprosy, especially for women, as the fear and stigma attached to the condition leads to psychological issues such as depression.

Though the law affirms the right to community and family life stating that no PwD shall be forced to live in any particular arrangements (Section 5 of the RPD Act, 2016), it does not do much in terms of ensuring safety from desertion and abandonment. Under the provisions for social security (Section 24 of the RPD Act, 2016) it makes specific mention of assistance for women with disabilities, corrective surgeries etc. but it limits it to the government's economic capacities. This would remain a mere distant promise unless a concrete and phased action plan is made for its realization.

Additionally, the various State beggary laws that criminalize beggary also impact persons affected by leprosy adversely, while mostly referring to them as lepers. Beggary is the only option for a majority of women affected by leprosy, and thus such laws end up criminalizing them and restricting their liberty by placing them in beggary homes. For example, there is a special beggary home for persons affected by leprosy and Tuberculosis in the Tahirpur area of Delhi. In a recent move, the Delhi High Court has de-criminalized beggary in Delhi and emphasized the need for rehabilitation (“Delhi court decriminalizes begging in national capital”, 2018) .

Challenges Going Ahead

The real challenge for the RPD Act, 2016 lies in taking its benefits to the invisible millions of leprosy-cured people who hide their condition, build other narratives about their deformities, and live silently in their communities under the constant fear of identification, discrimination and ostracism. If they are unwilling to come forward, how does the law intend to benefit them and provide for them? The key would lie in challenging the age-old attitudes towards leprosy, which could very much begin from the side of the government by removing the 119 legal provisions in Indian laws that directly discriminate against individual on the grounds of leprosy. As a welcome first step, the government introduced The Personal Law (Amendment) Bill, 2018 to remove leprosy as a ground for divorce from various Acts governing marriage and divorce in India. Yet, the road is a long one.

In the fight to eradicate leprosy, a holistic and gender sensitive approach is needed to engage not only on the issue of the disease, its disabling consequences and inclusion but also malnourishment, low levels of immunity, hygiene, sanitation and poverty. This would require a multi-pronged approach at all levels in coordination with a range of stakeholders and a great deal would depend on the will and the purse of the State.

End Notes

¹ As per WHO records of 1985, India had an estimated population of 7,30,540 people affected by leprosy in that year. Since then, it took India another 20 years to reach the elimination status of leprosy as a public health issue (meaning that one new case per 10,000 population is detected) and from 2005 onwards till date the National Leprosy Eradication Programme (NLEP) of the Government of India has been recording a rate of 1.25 to 1.35 lakh new cases every year. On the basis of this, it can be estimated that there should be approximately 10-12 million people affected by leprosy in the country.

² As NLEP data for 2016-17 a total number of 1,35,485 new leprosy cases were detected of which the female cases were 39.17%, NLEP Annual Report 2016-17, Ministry of Health & Family Welfare, http://nlep.nic.in/pdf/Annual%20report_%202016-17_rev.pdf (last accessed on 8th August 2018)

³ LCDC campaign refers to a door to door screening for unidentified leprosy cases in a given area under active case identification programs.

⁴ In the year 2017 alone, there were three cases reported in the newspaper where a deceased person affected by leprosy was not allowed his/her final rites in the village. One was buried in the hut he had been banished to live in, a woman was burned 3 kms away from her village in the forest and in another the family had to perform the last rites alone with no participation from the community.

⁵ ILEP is an international federation of anti-leprosy organisations working on the issue of leprosy across the world with a presence in India as well.

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