Indian J Lepr 2018, 90 : 35-45
© Hind Kusht Nivaran Sangh, New Delhi

http://www.ijl.org.in

Original Article

Violation of Human Rights of Leprosy Afflicted Persons: Some Real Life Experiences

P Dwivedi

Received : 25.07.2017 Accepted : 18.12.2017

In the present study an attempt has been made to understand the observance of marginalization and social exclusion of leprosy patients in their family and community and their violation of human rights. A total of forty (40) leprosy Afflicted Persons (LAPs), 20 without deformities and 20 having deformities were selected through stratified random sampling method from 'The Leprosy Mission Hospital (TLM)' of Allahabad district of Uttar Pradesh (India). Narratives of lived experiences of LAPs, supplement with observations, were used for data collection to observe the interaction patterns of LAPs with their family, neighbors and community members. The content analysis of data indicates that some of the LAPs experienced isolation and discrimination in their family, community and economic life. Some of the medical personnel also showed their hesitance in providing health services to them. It is also found that socio-economic problems became more in case of LAPs with visible deformities in comparison to LAPs who did not have deformities. Traditional cultural beliefs of the disease like the 'sin of previous birth', 'punishment of God', and 'fear of infection by germs', appear to be contributing to social, cultural, economic isolation of these patients. On the contrary lack of awareness about the ailment and also modern medical belief system like disease is not infectious and curable are may be helping in promoting their integration into their family and community, however, these aspects need to be studied in depth in current scenario. As present study is just based on some examples from a select group, it can not be considered as representative of all LAPs across the country which, however, should not be ignored at person level specially from the perspective of human rights. Health education programmes should be better implemented to prevent the physical disabilities, to reduce the traditional cultural beliefs and values associated with leprosy.

Key words : Leprosy-stigma, Violation, Human Rights, Marginalization, Deprivation

Introduction

World Health Organization (WHO) introduced the Multi Drug Therapy (MDT) successfully that declined the global prevalence of leprosy from 10 per 10,000 population in 1985 to 0.31 per 10,000 population in 2014 (WHO 2015). This WHO report of 2015 shows that out of total global new case detection of leprosy, most of the cases are reported from South East Asian Region (SEAR) accounted for 72%. Brazil, India and Indonesia all

---

Preeti Dwivedi, Assistant Professor, Department of Sociology, Mahila Mahavidyalaya (PG) College, Kidwai Nagar, Kanpur - 208011 Uttar Pradesh, India

Corresponding author : Dr. Preeti Dwivedi, **e-mail:** preetidwivedi70@yahoo.co.in

reported more than 10,000 new cases and accounted for 81% of new cases globally (WHO 2015). India reported 1,25,785 new cases in 2014 slightly less from 2013 which was 1,26,913 (WHO 2015). Besides medical aspects due to stigma and prejudices associated to leprosy affect the interactions of leprosy patients with other social units like family, neighbours, community, employers, access to public amenities and participation in cultural activities (Tekle-Haimanot et al 1992). A study in Gujarat showed that persons affected by leprosy are socially isolated and their behaviors are restricted in terms of using public facilities, sitting and eating together (Kant 1984, Ulrich et al 1993). Many of the leprosy afflicted persons loose their employment opportunities after the awareness of their ailment. A study in India reported that about 16-44% of the patients with leprosy reported the income loss after the onset of disease (Prabhakara Rao et al 2000). Sometimes schools' authority does not permit the younger patients to admit due to stigma afflicted with leprosy (de Stigter et al 2000). Family and community members isolate the leprosy afflicted persons from their home and villages on the pretext of infection by germs as found by Shetty et al (1985) in Mangalore city of South India. In some of the instances medical personnel also showed their unwillingness to treat the leprosy patients in India (Berreman 1984). Divorce rate of leprosy afflicted patients are also high as reported by Scott (2000). The patients afflicted with leprosy were unable to receive psychological, social and economic security from his/her respective spouse (Scott 2000). Kumar and Anbalagan (1983) also found that 23% of the respondents with leprosy were not living with his/her spouse. Kumar and Anbalagan (1983) also found that leprosy also attributed as a sole reason for not getting a life partner revealed by 67% of unmarried leprosy afflicted patients. On the other hand, Kathe and Naik (2000) in India investigated the effect of leprosy on the marital life of leprosy afflicted persons attending the Out-Patient Department (OPD) of leprosy centres in Mumbai city, India and observed that due to early diagnosis and successful treatment the spouse acceptance rate was of the order of 97% and only 3% of female patients with leprosy had severe disturbance in their married life at the time of confirmation of their disease as leprosy.

Due to fear of being stigmatized, patients do not want to disclose about their disease even in their family and also do not approach to the medical centre immediately (Bekri et al 1998). Delay in treatment increases the chance of disability and deformation. External manifestation of leprosy is reported as the major cause of stigma associated to the disease (Predaswat and Khi Thut 1992). Those with leprosy and visible signs experience more negative attitudes and perceptions in their community in comparison to those with leprosy but without deformities (Burathoki et al 2004). Rensen et al (2011) found in a study that leprosy patients with visible physical notions are restricted to participate the social functions than those who have not. Visible signs also enhance the fear of transmission of disease (Try 2006). Review of literature reveals that stigma associated with leprosy affects the quality of life of LAPs in terms of physical mobility, interpersonal relationships, marriage, employment, leisure and social activities (Wong 2004). Review of above studies also show that there are not many studies focusing on interactions of leprosy afflicted persons (LAPs) with their different social units like family, community, employers, medical personnel, access to public amenities and participation in ceremonies in family and community in a holistic perspective.

Human Rights are basic rights fundamental to all human beings regardless of caste, class, gender, region, religion or any other issue and are applicable everywhere and every time. Universal Declaration of Human Rights (UDHR) a milestone document drafted by different representatives with legal and cultural backgrounds from all parts of the world, proclaimed by United Nations in General Assembly held in Paris on 10 Dec 1948 by General Assembly resolution 217 (III) with a purpose to achieve a common standard for all peoples and nations. UDHR have their faith in fundamental human rights as every human being has his/her dignity and equal rights without distinction that promote social progress and betterment of living standard of human being. In India National Human Rights Commission (NHRC) was constituted on 12 Oct. 1993 under the protection of Human Rights Ordinance of 28 September 1993 that protect and promote basic fundamental rights relating to life, liberty, equality and dignity of an individual embodied in the International Covenants. It was given as legal basis by the protection of Human Rights Act, 1993 (TPHRA) of India. On the basis of such holistic perspective an assessment can be made to find out the violation of human rights in case of LAPs. Considering these issues the present study has been carried out to comprehend the nature of day-to-day interactions of leprosy patients with other social units and the implications of such interactions in the observance of human rights or their violation in terms of discrimination and isolation in family and community life, reduction of employment avenues and provision of medical care with hesitancy.

Materials and Methods

The present study is an empirical effort and a pilot study. For the same purpose forty (40) leprosy patients (20 without deformities and 20 having deformities) were selected from 'The Leprosy Mission' (TLM) Hospital, Naini, of Allahabad district through stratified random sampling method from out - patients and in - patients department for data collection. An interview schedule was constructed having open and closed ended questions pertaining to their interactions before and after the diagnosis of the ailments with their social units like family, community, employers, medical personnel and access to public amenities. Data collected through in - depth interviews were also supplemented with observations.

Results & Discussion

Content of the narrations are analyzed which reveals that these patients were experiencing deprivations along three themes i.e. *discrimination and isolation in family and community life, reduction of employment avenues and provision of medical care with hesitancy*. These themes are discussed separately along case materials in the following paragraphs :

(I) Discrimination and isolation in family and community life

Discrimination and isolation in family and community life is a state of separation from social and cultural life in their group and feeling of being disliked and alone which make them secluded and isolated. Thus discrimination and isolation in family and community life includes – *isolation and discrimination of patients from participation in ceremonies and rituals, living and sharing life of family and community members with leprosy patients with hesitations, divorced/separated by respective spouse, restricted to access the public amenities, restricted to share the household daily articles of living like bed, utensils, room etc. and force to leave their native place*. These subthemes are exemplified through selected quotations from the narrations and interviews of the respondents.

The interview extracts of respondents are mentioned here along case wise and referenced in the following manner: case 1; indicates that the quote is taken from the interviewee 1.

Case 8 was a 65 years old unemployed afflicted with leprosy before 10 years ago. He was cultivator before the advancement of his ailment but now could not work in the agricultural fields due to deformity of his hands. He lacked social support of his family and community after the advancement of his ailment. His living room was separated by his family members and it was outside of his home. Now nobody wanted to visit him after the advancement of ailment. He was restricted to take part in ceremonies and rituals. His statement in his own words had been: *"Before the onset of leprosy, I supported my younger brother economically and emotionally for continuing his education but after my disease and deformity he never visits me, never invites me in any rituals or ceremonial functions in his house*……

Case 30 aged 36 years was a petty shopkeeper suffering from leprosy before 7 years. Before the onset and advancement of the ailment he was agricultural labour. He had a wife and two children aged 7 years and 6 years in his family. He did not get the support of his neighbours and relatives except his family members after the advancement of his ailment. He had severe ulcer in his right insensitive leg from the last two months. He shared how he was restricted to visit their kin and neighbors. He stated, *"I was enjoying my life fully before the onset of leprosy. Everyone visited me but after the onset of my disease my neighbors and relatives avoid sitting and talking to me and restricted me to enter their homes and never invited me in rituals and ceremonies of their household."*

Community and family generally make a physical distance with leprosy patients and avoid talking, touching, sleeping and eating with the leprosy sufferers. In some cases daily articles of living such as room, bed, utensils, clothes etc. are separated for leprosy sufferers.

Case 27, aged 28 years was a housewife afflicted with leprosy after two years of her marriage i.e. before eight years ago. She did not accompanied by her in – laws and even by her husband to the hospital for health check – ups and medicines. Thus due to irregular medication her body became deformed. After the intensity of ailment, she was avoided by her in – laws and even by her husband. She had no children and had not sexual relations with her husband due to stigma afflicted with leprosy from last five years after advancement of ailment. Still she was living with them but in a separate room. She narrated as: *"After my ailment my room, bed, utensils are separated by my in – laws. Now people avoid entering my room and hesitate to sit on my bed."*

Leprosy has detrimental influence on marital relationship. In some instances it leads to divorce and it attacks on their self dignity.

Case 18 aged 38 years was a deformed leprosy patient suffering from leprosy with insensitive right leg before nine years. He was an agricultural labor. Due to hard physical work in the soil and insensitiveness in his leg he had ulcer again and again. He had his mother, wife and two children aged 4 and 7 years in his family. Before the onset of leprosy he had intimate and cordial relations with his wife but after the onset of increased intensity of the ailment he was avoided and ignored by his wife due to fear of contagious nature of the ailment. He told as: "……*before leprosy I ate meal together with my family members. My 'jutha'* (leavings of food on plate) *was eaten by my wife but now she does not share my meal and also does not eat together with me."*

Case 28 was 52 years old widow lady. She was suffering from leprosy before 18 years. She had a married son, daughter-in-law and four grand children. She did not get the support of his son or daughter-in-law after the onset of her ailment. Her husband who died before ten years abandoned her due to stigma associated to leprosy and married again. Presently she was living in a leprosy colony due to their humiliating behavior. She started begging as she had no option for her livelihood due to deformation. She stated, *"I was a housewife before my disease. My life was enjoyful but after the advancement of disease everyone in my in-law started to hate me. My in-laws called me 'korhi'. No one eat food or drink water touched by me. My husband abandoned me due to my disease and married again (weeping)*……….

Case 11 aged 31 years non-deformed leprosy patient suffering from leprosy before two years. He was a mason and did not complete the course of medicine due to carelessness and occupational concerns. He was living with his parents, wife and his children before the onset of ailment but presently only with his old parents. His wife divorced him due to fear of stigma associated to leprosy. He stated his experience in his own words, had been: *"…………….. I was very upset when my wife divorced me. She told me that she and our children could not live with me because I had contagious disease."*

Leprosy sufferers are forced to leave their home or they decided themselves to leave the home due to humiliation. In fact the following examples of narrations provide background information that highlights the causation of leaving the home:

Case 26 aged 48 years was a deformed leprosy patient suffering from leprosy before 13 years. Before the onset of ailment he was a carpet weaver but presently due to deformation became unemployed. He was living in a joint family with his wife, a married brother, sister-in-law, their children before two years. But presently he was living in a leprosy colony. He stated, *"After the onset of my ailment my room, bed, utensils and all daily articles of use were separated by my family. My wife and other family members called me 'korhi' and avoided my presence nearby, which hurt me deeply" (started weeping)*…. When asked, the reason for his leaving the village he responded *"Due to hatred and ignorance of my family and neighbors, I was very upset and decided to leave my village."*

Case 25 aged 47 years suffering from leprosy before 18 years. He had ulcer again and again due to insensitiveness. He lived in a separate cottage in his village due to discrimination and isolation of their family members. He told that: *"I am living in a separate cottage in my village because my family refused me to provide food and shelter. My family members insisted and forced me to leave the home and saying that if they allow me to stay in the family, the family will be stigmatized and kin and neighbors will refuse to visit their house, so they do not want to continue relation with me."*

Leprosy sufferers experience the problem in finding a marital partner of their daughters /sons /siblings. This is also one of the reasons of leaving the home.

Case 22 was 36 years old unmarried respondent suffering from leprosy before 14 years ago. He had ulcer in his right leg and right hand due to insensitiveness. He was a mechanic in a garage. Due to stigma associated with leprosy he was unable to get life partner. Due to fear of discrimination and degradation of social status he was insisted to leave the village by his family members. Presently he was living in a leprosy colony. His experience in his own words had been:

"I am hated and ignored by my family and community members. My family insisted me to live in a separate hut and saying that if I would live with them, then no one would be ready to marry with my younger brother."

It is unfortunate that a person afflicted with leprosy is deprived from using public amenities like public hand pumps, public ponds, public wells, auto-rickshaws, buses, trains etc which makes life miserable.

Case 21 was 50 years old widow lady suffering from leprosy before 17 years. She was living in a joint family with her two married sons, daughter-in-laws and grandchildren. One of her hand became deformed due to advancement of leprosy. Even after the advancement of her ailment she was supported by her sons and daughter-in-laws. But her neighbors and community members discriminated her due to fear of contagion. She responded as follows: *"My neighbors usually stop me to use the public wells and public hand pumps because I have leprosy……………………. I have deformed hand. I experienced problems in travelling because co-travelers do not want to sit beside me. Many of times co-travelers said me to leave the seats in buses or trains. In some occasions the co-travelers themselves move away from their seats after seeing my deformation."*

Case 1 was 61 years old deformed leprosy patient suffering from leprosy before 30 years. He was living in a leprosy colony alone since 22 years due to humiliation of his neighbors and community members, while supported by his family members. He had three married sons, daughter-in-laws and grandchildren in his family and they were living in the village. Sometimes his sons visited him in the colony take food – items and supported him economically too. He stated, *"In my house there was no toilet, so I used agricultural fields for natural cells. My neighbors disputed with me when I used their agriculture fields for toilet because I had leprosy…..the villagers of my community also stopped me to take bath near the public well."* Case 26 also stated his experience as : *"After the onset of ailment, the barbers of my village refuse me to provide their service. Barbers think that if they will provide services to me, then other people will not like to come their saloon. Due to fear of effect on their occupation they refuse to me."*

Narrations of above cases show that leprosy is not considered as a medical problem only but its detrimental effects on family and community life of the patients due to consideration of contagious in nature (Shetty et al 1985). Due to stigma associated to leprosy community members segregate them (Shetty et al 1985, de Stigter et al 2000). The rejection and segregation of some of LAPs by their neighbours and community members are shown in their participation restrictions such as ceremonies and rituals in the community, restricted to visit the neighbors' home and in using public amenities. Due to stigma afflicted with leprosy family members also reject the persons with leprosy (Scott 2000) and hesitated to live and share their life with them. Families also experience the problem due to having LAPs as a family member (Kopparty et al 1995). The socio – economic problems increased ten times more when the patients with deformity in comparison to those having patients without deformation (Kopparty et al 1995).

Case 27 also narrated his experience after deformation due to leprosy: *"…... after deformation I have experienced more social problem in my family and neighbor. When I have wound (ulcer due to insensitiveness) then everyone discriminate me more and sit and talk to me with hesitation".*

Leprosy also affect the cordial relations with intimate life partner as it attribute the sole reason for divorce or for not getting life partner for marriage (Kumar & Anbalagan 1983). Divorce rate of LAPs is high due to their inability to provide psychological, social and economic security and due to fear of transmission of disease (Scott 2000).

(II) Reduction of Employment avenues

Leprosy has also effect on occupation due to physical deformation and stigma associated with the ailment. Some of them started beggary as a source of their livelihood due to deformation and lack of social and economic support of their family and community.

Stigma is one of the causations of the income loss. One case of stigma related to income loss is found with case 4. He was 36 years old non – deformed leprosy patient and was working in a restaurant but now became unemployed. He had wife and one children in his family. He reported that: *"I was working in a restaurant. Only my employer was aware about my ailment in the restaurant. My employer fired me from the restaurant after awareness about my ailment. My employer said that when the other restaurant workers and customers will come to know about my ailment, they will stop coming to the restaurant."*

Some of the respondents also reported that due to physical deformity, they lost their employment opportunities and some of them started begging as a source of livelihood. Some interviews highlight the incidence of choosing beggary as a profession.

Case 14 was 55 years old leprosy sufferer was a labor in a brick kiln. Deformation in his hands inhibited his work activity therefore he could not continue his work. His family and community did not support him after his illness. He became alone. Due to deformity and lack of economic and emotional support of family he had no option except begging. He informed, *"I was labor in a brick-kiln but the disease has affected my hands. Due to effect of ailment I cannot hold things with my hands. I also did not get support of my family after the onset of my ailment……. I feel ashamed in begging but now there is no option left except begging."*

Case 28 also stated that: *"My son-in-law calls me 'korhi' repeatedly that hurt me deeply. My family members do not provide me food and insult me again and again. I have lost all fingers due to this ailment. Beggary is only option left as a source of my livelihood"……….*

Thus leprosy also reduces the occupational opportunities. Deformation seemed to be a major responsible source for loss of job (Kuppusamy et al 1979). Stigma associated to leprosy is also found as main reason for income loss or unemployment in several cases (Calcraft 2006). Due to fear of losing their job many LAPs do not want to disclose about their disease to their employers (Scott 2000). The physical deformation prevent the continuation of physically based employment and then in the absence of economic and emotional support of family or for their basic needs some of them started begging. Beggary among the leprosy affected person is the part of dehabilitation and an unwanted profession (Kaur and Van Brakel 2002). There is thus a need to rehabilitate LAPs to overcome from the disease and its socio – economic consequences.

(III) Provision of Medical Care with Hesitancy

The evidence of leprosy stigma is not limited to the family and community but the access of leprosy stigma also exists in the medical professionals. Some of the Doctors, nurses and paramedical staffs show unwillingness to provide medical care. Some examples highlight this point:

Case 18 also shared his experience: *"I have visible sign of deformity. A Doctor of private clinic drove me out of his clinic after awareness of my ailment. Doctor said me, "If you will come in my clinic then no other patient will prefer to visit my clinic."* Case 1 also informed that: *"I had fever, so consulted a Doctor (RMP) of my village. The Doctor showed his* *unwillingness to check me up due to my ailment." Further,* Case 4 stated, *"I had stomach-ache. I went to a Government Hospital. The Doctor covered his nose and mouth with a cloth during my treatment."*

Besides medical care leprosy sufferers also experience severe problems in getting bandage to their injuries. Due to leprosy they have ulcer and need to bandage but in the Government Hospital generally medical personnel refuse to provide bandage services. Case 22 also shared his experience, *"I had wounds in my one foot. The compounder of the Government Hospital refused to bandage and gave me medicines from a distance."*

Some in-patients of TLM Hospital shared their experiences which show how medical services in the Government Hospital differ from the Mission Hospital. Case 25 stated, *"I had wounds in my foot. In the Government Hospital the compounder refused to provide bandage services but in the Mission Hospital nurses provide bandage services without hesitation."* Case 19 aged 43 years suffering from leprosy before 2 years. He was living with his parents, wife and his five children. Due to fear of discrimination he did not disclose about his ailment in their neighbors and even in their family. He had ulcer in his thumb due to insensitiveness before 15 days. He shared his experience: *"I left the Government Hospital and came to the Mission Hospital because in the Government Hospital Doctors hated and also ignored me due to leprosy. I also experienced problems during bandage in the government hospital."*

Narrations of above cases show that some of the Doctors, Nurses and Paramedical Staffs also hesitate in treating the leprosy patients. A study on health personnel who were working for National Leprosy Eradication Programme (NLEP) in India also showed that 2/3 of the personnel had minimum desire of interaction with leprosy patients (Premkumar et al 1994). Some prejudices and misconceptions regarding leprosy still exist among health care workers like leprosy is considered as incurable disease and considered to be transmitted through touch (Briden and Maguire 2003). It is also found in the present study that stigma associated to leprosy is present among some health personnel of some government hospitals in comparison to the Missionary hospital. However, based on few examples narrated here general impressions can not be made, these observations only highlight the need of proper studies and appropriate interventions. To reduce stigma associated to leprosy an emphasis needs to be placed on education regarding transmission and low rate of infectivity of leprosy among health providers (Briden and Maguire 2003). Knowledge about leprosy and other stigmatized illness should be included in the basic nursing and medical curriculum in order to increase awareness and to decrease the stigma towards different stigmatized disease among health professionals.

The present study reveals that, even today some persons affected by leprosy experience social isolation, public restriction and alienation. Social isolation, public restriction and alienation make them marginalized and excluded group in their social environment. Leprosy is identified through deformities and ulcer. NLEP programme in India has resulted in major decline in patient load and early treatment which should have impacted social perceptions as well. However, its impact appears so deep rooted that despite the advancement of treatment and health education over the years, the negative beliefs and values are still present in sections of our society. Persons suffering from leprosy with deformity and ulcer experience more social isolation, public restrictions, deprivation and discrimination than leprosy patients without deformity and ulcer. For example, Case 25 narrates: *"My one of the legs has deformed due to leprosy. After deformation I have experienced more social problem in my family and neighbor. When I have wound then everyone discriminate me more and sit and talk to me with hesitation."*

Traditional cultural beliefs like the disease has been considered as the 'divine punishment', 'sin of previous birth' and 'evil spirits' leads to such negative behaviors. It is also found that, due to lack of scientific knowledge and definite facts about the causation of leprosy, leprosy is considered as a very contagious disease. This is also a major factor involving in the negative family and community behavior towards leprosy sufferers. The misconceptions regarding the disease that it is contagious in nature among some of the medical personnel of government hospitals needs effective training in the medical aspect of leprosy besides educating the members in their family and community. The following examples highlight this point: Case 25 reported, *"................. I am living in a separate cottage as my family members told me, 'if I would stay with them, disease might spread to other members in the family'. Further,* Case 4 stated, *"After awareness of my ailment owner of restaurant where I was working fired me due to fear of being infected and told me that I had a contagious disease so he could not allow me to work here".*

Case 28 stated, *"Members of my family and community tell me that due to past misdeeds of previous birth and divine punishment I am suffering from leprosy in the present birth."* Case 18 narrated, *"…..after the onset of ailment everyone sits and talks me with hesitation. Everybody tell me that due to evil spirits my body became deformed."*

Conclusion and future perspectives

Considering the issues of social isolation, reduction of employment avenues, provision of medical care with hesitancy and restrictions from the access to public amenities, the result of this study show that a section of leprosy patients become marginalized and excluded group in the society. Due to exclusion and marginalization some fundamental human rights (according to Universal Declaration on Human Rights, UDHR) are not observed in case of leprosy patients in general:

- ➢ Those suffering from leprosy are less free to lead their own lives as a person affected by leprosy is being rejected and excluded from the society and so denied of the article 1 of UDHR. According to Article – 1 of UDHR – *'All human beings are born free and equal dignity and rights.'*
- ➢ Those having leprosy experience social isolation and public restrictions which impede the realization of both the rights as mentioned in Article – 2 (*All rights and freedoms are equal for all human beings without any distinction*) and Article – 3 (*Everyone has the right to life, liberty and security of person*) of UDHR.
- ➢ Leprosy sufferers deprived from the access of public amenities thus they are denied from the right of equal access to public services (Article – 21(2)).
- ➢ Employers may fire a person who once had leprosy so the right of work participation is denied (Article 23 (1)).
- ➢ Due to physical deformity and lack of social and emotional support, persons affected with leprosy start begging as a source of livelihood, as other sources of livelihood are denied. Members of family and community

discriminated them from home due to stigma associated to leprosy and traditional cultural beliefs. Medical personnel also show their unwillingness to provide medical care. Thus the patients with leprosy also deprived from the Article – 25(1) of UDHR as Article 25 (1) includes – *"Everyone has the right to a standard of living adequate for the health and well – being of himself and of his family."*

- If some persons affected with leprosy are not allowed to take part in social and cultural activities like rituals, marriage, and social gathering and are segregated from the society is violation of Article 27 of UDHR as according to Article 27 – 'Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits'.

Thus leprosy continues to be more than a disease. While it can be medically cured, but the social implications of leprosy still remain in a section of LAPs as well as community. It is also reported by leprosy patients that the patients do not want to disclose about their disease due to fear of being discriminated in the family and community life and therefore they approach to the medical center at the advance stage of the ailment. Patients having deformation experience more socio-economic problems than non-deformed sufferers. Thus leprosy makes some of the patients marginalized and excluded group in some cases. As present study covers just some examples from a select group, it has limited implications, which however, should not be ignored at person level specially from the perspective of human rights. As stigma to leprosy has been present across the globe, these issues require attention all over. Health education programmes should be better implemented to prevent the physical deformity, to reduce the traditional negative cultural beliefs and values associated with leprosy.

Acknowledgments

I would like to express our sincere thanks to all the medical staff of Mission hospital and all leprosy patients for their assistance to conduct this study.

References

1. Bekri W, Gebra S, Mengiste A et al (1998). Delay in presentation and start of treatment in leprosy patients: A case – control study disabled and non – disabled patients in three different settings in Ethiopia. *Indian J Lepr.* **66**: 1-9.
2. Berreman J (1984). Childhood leprosy and social response in South India. *Soc Sci Med.* **19**: 853-865.
3. Briden A, Maguire E (2003). An assessment of knowledge and attitudes towards leprosy / Hansen's disease amongst health care workers in Guyana. *Lepr Rev.* **74**: 154-162.
4. Burathoki K, Varkevisser C, Lever P et al (2004). Gender, leprosy and leprosy control: A case study in the Far west and Eastern Nepal. Royal Tropical Institute, KIT Publishers/NLR, Amsterdam, The Netherlands.
5. Calcraft J H (2006). The effects of the stigma of leprosy on the income generation of leprosy affected people in the *Terai* area of South East Nepal. *Asian Pacific of Disability and Rehabilitation Journal.* **17**: 73-89.
6. de Stigter, de Gaus L, Heynders M (2000). Leprosy between acceptance and segregation: community behaviors towards persons affected by leprosy in Eastern Nepal. *Lepr Rev.* **71**: 492-98.
7. Kant VP (1984). Socio-economic problems of leprosy patients and their relatives in Gujarat state. *Indian J Lepr.* **56**: 889-900.
8. Kathe VJ, Naik SS (2000). Leprosy patients and their spouses. *Indian J Lepr.* **72**: 248-249.
9. Kaur H, Van Brakel W (*2002).* Is beggary a chosen profession among people living in a 'leprosy colony'? *Lepr Rev.* **73**: 346-355.

10. Kopparty SNM, Kurup AM, Sivaram M (1995). Problem and coping strategies of families having patients with and without deformities. *Indian J Lepr.* **67**: 133-152.
11. Kumar A, Anbalagan M (1983). Socio-economic experiences of leprosy patients. *Lepr India.* **55**: 314-321.
12. Kuppusamy P, Richard J, Selvapandian AJ (1979). A study of causes of unemployment among agricultural labourers afflicted by leprosy. *Lepr India.* **51**: 370-76.
13. Prabhakara Rao V, Rao IR, Palande DD (2000). Socio-economic rehabilitation programme of LEPRA India – Methodology, Results and Application of needs – based socio-economic evaluation. *Lepr Rev.* **71**: 466-471.
14. Predaswat P, Khi Thut (1992). The disease of social loathing: An Anthropology of the stigma in rural Northeast Thailand (Ph.D Thesis), University of California.
15. Premkumar R, Kumar KS, Dave SL (1994). Understanding the attitude of multidisciplinary teams working in leprosy. *Lepr Rev.* **65**: 66-67.
16. Rensen C, Bandyopadhyay S, Gopal PK, Van Brakel WH (2011). Measuring leprosy – related stigma – A pilot study to validate a toolkit of instruments. *Disabil Rehabil.* **33**: 711-719.
17. Scott J (2000). The psychosocial needs of leprosy patient. *Lepr Rev.* **71**: 486-91.
18. Shetty JN, Shivaswamy SS, Shirwadkar PS (1985). Knowledge, attitude and practices of the community and patients regarding leprosy in Mangalore – A study. *Indian J Lepr.* **57**: 613-619.
19. Tekle – Haimanot R, Forsgren L, Gebre-Mariam A et al (1992). Attitudes of rural people in central Ethiopia towards leprosy and a brief comparison with observations on epilepsy. *Lepr Rev.* **63:** 157-168.
20. Try L (2006). Gendered experiences: Marriage and the stigma of leprosy. *Asia Pacific Disability Rehab J.* **17**: 55-72.
21. Ulrich M, Zulueta, AM, Caceres-Dittmar G et al (1993). Leprosy in women: characteristics and repercussions. *Soc Sci Med.* **37**: 445-456.
22. Universal Declaration of Human Rights, UN General Assembly, 10 Dec. 1948, 217 A (III).
23. World Health Organization (2015). *Weekly Epidemiological Record No. 36.*
24. Wong ML (2004). Designing programmes to address stigma in Leprosy: issues and challenges. *Asia Pacific Disability Rehabilitation Journal.* **15**: 3-12.

How to cite this article : Dwivedi P (2018). Violation of Human Rights of Leprosy Afflicted Persons: Some Real Life Experiences. *Indian J Lepr.* **90** : 35-45.