

Psychosocial aspects of Hansen's disease (leprosy)

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ABSTRACT

In general, the prevalence of psychiatric disorders among people with Hansen's disease has greatly increased to date. However, inadequate psychiatric care of people with Hansen's disease is an area of increasing concern. Many studies have been conducted in India and abroad to find out the prevalence of comorbid psychiatric disorders in patients suffering from Hansen's disease. Although efforts have been made by the government and international organizations to solve the medical problems among this group of patients, this disease still carries a number of psychosocial issues. The social stigma connected to these patients makes this disease completely different from others. Even nowadays people affected by Hansen's disease have to leave their village and are socially isolated. Depression is the most common psychiatric disorder found in these patients. Early detection and treatment of psychiatric disorders among Hansen's disease patients is a powerful psychotherapeutic measure. Integrated healthcare strategy will be beneficial to these patients. A comprehensive MEDLINE search and review of relevant literature was carried out and the data extracted and studied with particular reference to psychosocial issues in Hansen's disease. The focus of this research work is related to psychiatric and social aspects vis-à-vis stigma in these patients with Hansen's disease.

Key words: Anxiety disorders, depressive disorders, Hansen's disease, leprosy, stigma

INTRODUCTION

Throughout history, leprosy has been feared and misunderstood. The origin of leprosy is unknown. The disease was first described around 600 BC. There was a debate in 1960s and 1970s about the choice of appropriate name for this disease - leprosy, lepra, Hansen's disease or Hanseniasis.^[1-5] A strong movement developed in some countries to substitute the name Hansen's disease for leprosy.^[6] The disease is an important cause of crippling deformities.^[7] The affected people have high psychosocial problems such as divorce, unemployment, and displacement from their native place of residence.^[8,9] Psychiatric disorders are highly prevalent in people with Hansen's disease and these preoccupy the healthcare resources. Comorbidity among these patients is observed in both clinical and epidemiological studies.^[4-22]

EPIDEMIOLOGICAL STUDIES

Many studies have been conducted in India and abroad to find out the prevalence of comorbid psychiatric disorders in patients with

Hansen's disease. Varying results have been documented in the literature obtained from different geographical regions of the world. In an Indian study conducted by Kumar and Verghese in 1980, the prevalence of psychiatric morbidity in Hansen's disease affected population was higher (99/1000) in comparison to the general population (63/1000).^[10] In 1903, the incidence of psychiatric disorders among these patients was found to be less than 6%.^[11] Monrad-Krohn *et al.* revealed that there is no particular form of psychosis directly associated with Hansen's disease and this disease plays the role of psychogenic inducement in the patients who are constitutionally predisposed to psychiatric disorders.^[12] In 1927, Cazenavette and in 1931 Muir reported that the incidence of psychosis among these patients was 3%.^[13,14] Price in 1983 identified that 70% of these patients felt psychological problems mainly due to the association between physical deformity caused by Hansen's disease and the accompanying disease associated stigma.^[15] In 1984, Ramanathan reported a high frequency of psychiatric disorders (55%) in these patients.^[16] Yazici *et al.* found that 20% of patients with

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Hansen's disease utilizing outpatient services were found to have comorbid psychiatric disorders.^[17] Chatterjee *et al.* reported a high frequency of psychiatric disorders (64.7%) in these patients.^[18] Verma and Gautam in 1994 conducted a study on 100 confirmed patients of Hansen's disease and found that 76% of them were having comorbid psychiatric disorders.^[19] Leekassa *et al.* in a study in a specialized hospital of Ethiopia found that 52.4% of the study subjects with Hansen's disease were having psychiatric disorders.^[20] Kisivuli *et al.* from Kenya showed that the prevalence of psychiatric morbidity was 53.29% among people with Hansen's disease.^[21] The psychiatric morbidity was found to be positively correlated with physical disability and marital status but not with age, sex, education, type of Hansen's disease, or duration of the illness. Erinfolani *et al.* in a case-control study concluded that patients of Hansen's disease were more likely to manifest with psychiatric disorders than those suffering from other skin conditions.^[22]

STIGMA AND HANSEN'S DISEASE

Problems of divorce, economic deprivation, and displacement from families

Society maintains negative feelings toward people with Hansen's disease. Problems of divorce, unemployment and displacement from area of residence are common in people affected with Hansen's disease.^[8,9] Stigma attached to these patients has more impact on educated women belonging to a higher socioeconomic group and in joint families.^[23] Because of the fear of infecting family members, women sufferers keep themselves aloof and are constantly worried about divorce. The psychosocial issues that are commonly related to stigma are people's dignity, social status, employment opportunities, job security, family relationships, and friendships. People have left their families and even spouses and children, fearing the repercussions of the fact that they had Hansen's disease. Eldaron *et al.*, in a study on divorce among Saudi female patients, concluded that the average rate of divorce mainly because of Hansen's disease was 14.4% in Saudi women.^[24] Kaur and Ramesh in 1994 in a study on social problems of women patients showed that the impact of stigmata attached with Hansen's disease had more effect on educated women belonging to a higher socioeconomic group than on less fortunate women. Discriminative attitudes were more common in joint than nuclear families. Although many got support from their families, the disease had definite psychological effects. The fear of social ostracism prevented the disclosure of disease to the community. As far as the relationship with the community was concerned, communities of 32% patients were aware of their diseased condition and 31.25% of these patients were not allowed to use common community places. At the family level, in spite of a cooperative attitude from the husband, 25.6% women were worried about divorce, 62% of women had

a tendency to get angry over trivial matters, and 30% of them also preferred to remain alone.^[8] Raju and Reddy in a study in Andhra Pradesh and Orissa on community attitude to divorce in Hansen's disease revealed that a substantial number of persons favoured divorce from the Hansen's disease-afflicted spouse.^[25] Raju and Kopparty in a study found that lack of knowledge, understanding, and incorrect beliefs regarding Hansen's disease are responsible for continuation of the stigma cycle.^[26] Vlassoff *et al.* gathered data from 2495 inhabitants of Bihar and Maharashtra and the findings of this study concluded that the impact of Hansen's disease was greater for women because they suffered more isolation and rejection than men.^[27] Calcraft in a study on the effects of the stigma of Hansen's disease showed a negative effect on income generation among the affected people in the Terai area of south east Nepal. The negative physical effects of the disease were the main reason for lost income and employment status.^[28]

DEFORMITIES AND TREATMENT DROPOUTS

Awofeso in a study on stigma and socio-economic reintegration of Hansen's disease sufferers in Nigeria concluded that Hansen's disease is the most common cause of peripheral neuropathy in the world.^[29] Hansen's disease complications can cause gross deformities of the face and limbs of infected individuals as well as crippling disabilities involving sight, touch, and manual dexterity. Such stigmata intensified the social and economic isolation of patients. Although concerted efforts by national Governments and international organizations have achieved a major breakthrough in eradication of this disease from in most parts of the world, Hansen's disease still remains a human problem. About 30% of past or present Hansen's disease sufferers in Nigeria are disabled and/or handicapped as a result of the disease.^[30] Stigma may affect many aspects of National leprosy eradication program and Government health policies. Bekri *et al.*, in a case-control study of disabled and nondisabled patients in three different settings in Ethiopia, showed that the stigma is an important factor associated with delay in presentation.^[31] Fear of being found to have Hansen's disease and the possible consequences of this fear may even lead to discontinuation of treatment. Some employers refuse to employ even a cured patient of leprosy.

Koteeswaran in a study on treatment dropouts revealed that a significant portion of these patients met with a rejecting attitude and their marital relations were strained. Their family members were said to be hostile and noncooperative in providing them treatment and social support.^[32] Most patients delayed seeking help for over a year. This resulted in complications which could definitely have been prevented.^[33] Ogden and Porter in a study on Hansen's disease showed that stigma against these patients affects all aspects of disease control. The social consequences

of the disease on the life of the patient persist even after its cure.^[34] Sanjay *et al.* in a study observed that these patients were isolated and refrained from various activities in the family. Deformities and disabilities led to deterioration in their functional capabilities and their psychological state of mind.^[35] Senturk and Sagduyu in a study on psychiatric disorders and disability among Hansen's disease patients showed that the social stigma connected to these patients makes this disease completely different from others. The physical deformity ratio is approximately 25% in these patients.^[36] Ratna Philip demonstrated the effect of deformity on psychosocial aspects of people with Hansen's disease.^[37]

INMATES AMONG LEPROSY COLONY

Kaur and Brakel attempted to look into the lives of the Hansen's disease affected people living in a leprosy colony. Due to Hansen's disease, the social interaction of the 85% of the interviewees was limited to within the colony. Through their own organized efforts, they raised welfare services and housing for themselves. None of them liked begging to start with but have accepted it as a source of income. If given a chance and support, 80% said they were ready to quit begging.^[9] Brackel found that Hansen's disease stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. Despite enormous cultural diversity, the areas of life affected are remarkably similar. They include mobility, interpersonal relationship, marriage, employment, leisure activities and attendance at social, and religious functions.^[38]

Kaur and Gandhi in a study on people's perception of leprosy revealed that the knowledge of leprosy among general population was inadequate.^[39] The cause of the disease was known to only 44.2% of the study participants, while 31.7% of the study subjects were completely ignorant about the disease, 6.7% of them believed it to be the consequence of the individual's past misdeeds. A total of 63.1% of the study participants were aware that the disease is curable; 73.1% of the persons interviewed sympathized with Hansen's disease-afflicted beggars; 61.5% of the subjects favoured Hansen's disease patients to stay with their families and within their communities; 67.3% of the subjects felt that the cured could marry, while 25% of them felt that the leprosy afflicted should live in leprosy colonies away from the society. A total of 54.8% of the study participants were reluctant to employ the Hansen's disease afflicted as domestic help, and 31.7% were reluctant to establish matrimonial relationship with a family having a Hansen's disease afflicted person.^[39] Briden and Maguire in a study showed that knowledge of the disease among sufferers was relatively good, but that certain facts were not widely known. Fifty percent of the respondents did not know that Hansen's disease is now curable. Although most respondents did not display prejudice in their own responses, many implied that prejudice was still present in the wider

community. A significant minority believed that patients should be kept apart from other people.^[40]

PSYCHIATRIC DISORDERS IN PEOPLE WITH HANSEN'S DISEASE

As the people affected with this disease are rejected by the local community and family members, they are forced to stay in ashrams, mandirs, and leprosy homes. As a result of these problems, patients with Hansen's disease are associated with a high risk of developing psychiatric disorders. The prevalence of psychiatric disorders among these patients is higher than that among the general population. Another important finding is that the long duration of the illness and physical handicaps raise the risk of psychiatric disorders.^[41] Comorbidity among patients with Hansen's disease is particularly common and may have significant implications in terms of choice of treatment.

DEPRESSIVE DISORDERS

Depression is the most common psychiatric disorder among these patients. Takeuchi in a detailed study on the psychiatric aspects of patients concluded that emotional aspects undergo the greatest change among Hansen's disease patients.^[42] Behere found that majority of the patients were suffering from depressive disorders.^[43] Mhasawade found similar types of psychiatric disorders in these patients.^[44] Ramanathan reported that depressive disorders were the commonest findings in these patients.^[16] Olivier in a study of psychiatric disorders among patients of Hansen's disease by using the Diagnostic and Statistical Manual of Mental Disorders 3rd Edition (DSM-III) showed that 46% of these patients were found to have an affective disorder.^[45] Ma *et al.* in east China found a higher suicide rate in leprosy patients compared with the general population.^[46]

Reddy reported that the most common diagnosis found among leprosy patients was dysthymia.^[47] Verma and Gautam in New Delhi examined psychiatric comorbidity in 100 confirmed patients with Hansen's disease and it was revealed that 76% of the patients were found to be having psychiatric illness. Of these, a large number of the patients (55%) were having neurotic depression and 21% had anxiety neurosis.^[19]

Philip reported that 33.34% of the Hansen's disease patients reported suicidal ideation after developing deformity and 23.34% were worried about their future.^[37] Saylan *et al.* reported the degree of depression in leprosy patients by using Beck and Hamilton depression scale and revealed that 70% of the patients had depression of moderate and severe degree.^[48] Tsutsumi in a study concluded that depressive status of leprosy patients was significantly more severe than that of the comparison group.^[49]

ANXIETY DISORDERS

Shale in a study on women with leprosy showed that anxiety disorders were more commonly found in people with Hansen's disease.^[50] Bhatia *et al.* in a study on psychiatric morbidity and pattern of dysfunction in patients with leprosy showed that the predominant psychiatric illness in study group was generalized anxiety disorder (27.8%), followed by mixed anxiety and depressive disorder (13.3%), psychosexual disorder (2.2%) and one case (1.1%) had delusional parasitosis. The mean GHQ score of the Study Group was 3.44 (SD 4.04) with a range of 0--12 whereas the mean GHQ score in the control group was 1.62 (SD 1.76) with a range of 0--5.^[51]

NEED FOR COMPREHENSIVE PSYCHIATRIC CARE

Despite the various policies adopted for complete eradication of Hansen's disease, psychosocial rehabilitation of these patients is a challenging task. There is an urgent need for comprehensive psychiatric care for people with Hansen's disease. There is requirement for better coordination between leprologists, dermatologists, healthcare personnel, and mental healthcare professionals for the integrated healthcare of these patients. Early detection and treatment of psychiatric disorders among these patients is a powerful psychotherapeutic measure. Integrated healthcare strategy will be beneficial to these patients. Majority of the studies emphasized the frequent occurrence of depression and anxiety disorders in these patients. These patients have loss of self-confidence, diminished capacity to cooperate, diminished capacity for employment, and loss of self-respect. As the mental health problems of this group of patients originate from social attitudes toward leprosy, an attitudinal change is the need of the hour. From every standpoint, any steps taken to minimise the emotional burden brought on by Hansen's disease are important.^[52] Health education is the most important measure in tackling this health problem. Mhasawade recognized that psychiatric treatment is not being practiced in institutional cases of Hansen's disease.^[44]

The benefit of recent advances in psychiatry and the information regarding availability of safer psychotropic drugs and psychosocial methods of treatment has not been passed to this subgroup of patients. Despite documented evidence of safety of newer treatment approaches and better outcome, the public opinion toward these patients has not changed much. The public is largely ignorant of the success stories of a better outcome from comorbid psychiatric disorders in this population and hence it harbours many misconceptions relating to the cause and care of persons with Hansen's disease.

Psychological rehabilitation of these patients is dependent on the interpersonal relationship between the patient and

healthcare worker. The healthcare worker dealing with these patients is the primary link between the patient and normal existence. This link needs to be strengthened and the patient should be respected as a person and brought to the mainstream of society. The family relationships of these patients need to be preserved by every possible means. The focus of psychosocial rehabilitation lies with the family and family protection and other measures should be adopted in a dignified way.

FUTURE DIRECTIONS

There are many hurdles for the complete eradication of Hansen's disease from this universe. Even though much work has been done and success obtained in many countries, the human problem of stigma remains. Leprosy eradication is a long-term activity. Chemotherapy alone is not sufficient to solve all treatment issues. The role of mental health professionals is important in tackling psychosocial issues related to Hansen's disease. Psychosocial assistance and support to the affected population of this disease will be helpful in eradication of this disease. This requires a national-level mass campaign of health education for the general public. The general public should be made aware that Hansen's disease is not a genetic disorder, it is 100% curable, and the patients need social support. A better coordination between all healthcare partners like leprologists, dermatologists, psychiatrists, healthcare workers will settle all the issues and help in achieving the eradication goals.

CONCLUSION

There is a substantial need for providing comprehensive psychiatric care to the patient afflicted with Hansen's disease. The first part of this review examines the various epidemiological studies conducted in India and abroad and these studies have given variable prevalence rates of psychiatric disorders in this group of patients. Social stigma has a significant role in inducement of psychological disorders in patients with Hansen's disease. The second part of the review demonstrates the subtypes of psychiatric disorders found in these patients. Depression and anxiety disorders were predominantly detected in these patients. Early detection and treatment of psychiatric disorders among these patients is a powerful psychotherapeutic measure.

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