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# Stigma Experience in Skin Disorders: An Indian Perspective

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Stigma is inherently integrated in different aspects of Indian life, especially with certain diseases. Since time immemorial, tuberculosis, cancer, leprosy, and mental illnesses were stigmatizing, until HIV infection became prevalent over the last two decades. Stigma in Indian society is also related from ancient times to certain castes and the lower socioeconomic strata of people. Illnesses in these sections of society are even more stigmatizing. Stigma is related to tradition and philosophy, and to appearance. Skin color and complexion, and other qualities in its appearance, influence public opinion and attitudes, especially prejudice. Skin diseases that alter skin complexion or color, texture, or appearance in any way induce negative emotions in others. This leads to social isolation, seclusion, discrimination, and ostracizing of such persons from their neighborhood or community. This stigma experience in relation to skin diseases has been prevalent in Indian societies since ancient times. as evident from ancient Indian writings and scriptures. The great ancient Indian physician Sushruta in his medical treatise Sushruta Samhita (600 BC) gives a fairly good description of leprosy, which was prevalent in India from olden days. A fatalistic attitude prevailed and leprosy was considered a curse of God, a myth, sanctified by religious beliefs and surrounded by superstitious fears, dread, and ostracism of the patient, leading to mental suffering, social dis-

location, and serious socioeconomic difficulties for the patient [1].

Stigma is a society's negative evaluation of particular features or behavior. There is a great deal of variability in approaches to define stigma. Goffman [2] defined stigma as an "attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one." Stafford and Scott [3] defined stigma as "a characteristic of persons that is contrary to norm of a social unit," where a norm is defined as "shared belief that a person ought to behave in a certain way at a certain time." Healthy looking skin is the normal, and skin disorders, which change the color or appearance of the skin, attract attention and usually disgust and social reactions. Social labeling and social stigma are interrelated. The culmination of stigma process occurs when designated differences lead to various forms of disapproval, rejection, exclusion, and discrimination [4]. Varied dimensions of stigmatized medical conditions include the nature of the illness. its history, and attributed characteristics; sources of creation and perpetuation of stigma; the nature of the population who are perceived to carry the illness; the kind of treatment and practitioners sought for the condition; and how individuals with stigmatized medical conditions, including skin disorders, cope with societal insults that endanger their personal identity, social life, and economic opportunities [5].

Studies on psychosocial aspects of dermatologic disorders in India have neither addressed stigma directly, nor in much detail. There are some studies on the prevalence and type of stigma, which is in relation to leprosy. There are a few studies that have

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discussed social consequences and impact thereof, psychosocial reactions, and adjustment issues. There are some studies, reviewed later, which have determined the prevalence and nature of psychosocial problems with skin disorders in the Indian subcontinent. It is mere speculation that the psychologic reactions in patients with skin disorder can to some extent reflect the social impact of their skin disorders.

## Psychosocial aspects of skin disorders in India

There are a few studies on psychiatric and psychologic aspects of skin disorders from the Indian settings. Sharma and coworkers [6] studied and compared the psychiatric morbidity in five chronic and disfiguring diseases: (1) psoriasis, (2) chronic urticaria, (3) leprosy, (4) vitiligo, and (5) lichen simplex chronicus. The overall prevalence of the psychiatric morbidity was found to be 39%; common symptoms were depression (13%), anxiety (11%), suicidal ideations (16%), and somatization (13%). Interpersonal conflict was noted in 10% and suicidal attempts in 3%. Psychiatric morbidity was significantly higher in the psoriasis (53%) than vitiligo (16%) patients. A total of 23% of psoriasis and 10% of vitiligo patients reported depression. Sleep disturbance was significantly more often reported by psoriasis patients (57%) than vitiligo patients (20%).

In another study, Agrawal and coworkers [7] conducted a survey in Nepal to study the clinical profile of 210 psoriasis patients and also to assess their beliefs about their disease. The strongest belief of the patients in the causation of psoriasis was germs or virus (75%). Most patients believed that psoriasis had a major consequence on their lives (81%) and that psoriasis was a serious condition (83%). Women were significantly more likely to believe that their psoriasis had severe consequences on their lives.

Pulimood and coworkers [8] found a prevalence rate of 9% using the International Classification of Diseases—10th revision diagnostic criteria, more commonly in patients receiving long-term high-dose steroids. Psychiatric morbidity was associated with a longer duration of hospital stay and more frequent admissions. The commonest illnesses were depressive episodes (34%) and adjustment disorders (29%). Bagadia and coworkers [9] found a prevalence rate of 37% on using a screening instrument, and 49% with a clinical interview.

The psychiatric and psychosocial morbidity of some of the common skin disorders in India are discussed next. Psoriasis

The psychiatric comorbidity in patients of psoriasis greatly affects their quality of life and the course of the disease. Psychiatric comorbidity (anxiety and depression [10]) and poor quality of life, more so in women [11], have been reported. Patients reported avoiding communal baths, wearing uncomfortable clothes to cover diseased parts, inhibition of sexual relationship, suicidal ideation, and economic constraints in pursuing treatment and ineffectiveness of topical therapies. These behaviors can be considered to emerge from prevailing social norms and restrictions. A comparative study [12] of psoriasis and leprosy patients revealed higher presence of psychiatric morbidity in psoriasis (48%).

Chaudhury and coworkers [13] observed that patients with psoriasis had a psychiatric morbidity of 24% (predominantly with alcohol dependence) and scored significantly high on presence of anxiety, depression, trait presence of alexithymia, and stressful life events as compared with healthy controls and those with fungal infections. Deshpande and coworkers [14] noted a high degree of psychiatric morbidity (65%), mainly anxiety and depressive disorders. No study has attempted directly to address the issue of stigma in psoriasis patients, although social issues were addressed by some [9,11,15].

Vitiligo

In India, vitiligo is a common pigmentary disorder of great social and cosmetic concern. Since ancient times, patients of vitiligo have suffered the same physical and mental abuses as leprosy of that age and they were considered to have "Sweta Kushta," meaning white leprosy. It is particularly disfiguring in people with dark skin and causes such a severe social stigma in Indian society that patients are considered unmarriageable [16], and women developing vitiligo after marriage have marital problems perhaps culminating in divorce. The first Prime Minister of India, Pandit Jawaharlal Nehru, ranked vitiligo as one of the three major medical problems of India, the other two being leprosy and malaria. In India, vitiligo, commonly known as "leukoderma," is unfortunately associated with certain myths, superstitions, and adverse religious beliefs. In some Indian religious texts where reincarnation is believed, it is said that a person who had done "Guru Droh" (meaning "had insulted teacher") in his or her previous life suffers from vitiligo in the present life. People suffering from vitiligo in India may have more and quite unique psychosocial problems than in other countries [17]. In a study [17] in North India, 150 patients of vitiligo had a mean Dermatology Life Quality Index score higher than that obtained by Finlay and Khan [18], indicating greater impact on their quality of life. Indian people have a pigmented skin predisposing them to prominent observable effects of hypopigmentary disorders like vitiligo. The psychosocial milieu of the developing countries being different from that of the developed countries, the stigma associated with hypopigmentation or depigmentation is possibly more severe in colored races inhabiting most of the developing world [19,20].

## Leprosy

Leprosy is still a major public health problem in India, even though the prevalence rate has come down from 57.6 cases per 10,000 population (1981) to 2.7 cases per 10,000 populations (September 2003) [21]. Reduction in prevalence rate alone, however, is not sufficient because the social consequences of the disease on the life of patients are often severe and persist even after its cure. Leprosy is a highly stigmatized disease. Misconceptions about leprosy including beliefs that it is contagious, incurable, and hereditary or a consequence of divine punishment all contribute to stigma in many societies. Many studies done in India have confirmed the high prevalence of psychiatric morbidity in persons affected by this condition. Kumar and Verghese [22] found psychiatric morbidity in the community to be 99 per 1000 in comparison with 63 per 1000 in the general population. Most of the studies on psychologic aspects of leprosy have stressed the role of social stigma [22,23]. Psychiatric morbidity was noted to be positively correlated with physical disability; knowledge about disease and social, emotional, and health maladiustment; but not with duration of illness [24]. Gender bias has been observed and social impact on daily life has been more in females than males as revealed by isolation from daily activities, such as restrictions on participation in familial functions and touching children [25,26]. Behere [27] observed that 58% expressed suicidal ideas, 8% had made suicidal attempts, and there was a negative correlation between psychologic symptoms and duration of illness, indicating that some adaptation occurs with time and maybe intervention.

Leprosy is probably associated with maximum degree of deformity, disability, and social stigma [28]. Because of medical advances, there has been a considerable reduction in the stigma in the last 50 years. It is only in the last few years, however, that the social dimension is being increasingly recog-

nized as critical to the process of rehabilitation of these patients and being incorporated into the various leprosy control programs [29].

Since the early 1980s, there have been studies on leprosy patients emphasizing the presence of psychiatric morbidity [12,23,27,30]. Patients had more negative attitudes toward their illness, most commonly illness evokes public fear and hate, illness is degrading and humiliating, they should be segregated from society, and illness is incurable and is a consequence of sins. Segregation from family (by being inpatients) accentuated the negative attitudes and associated stigma [23]. Subsequently, 100 displaced or migratory leprosy patients in a center in North-West India were studied [31,32] for presence of psychiatric morbidity and its correlates. A very high prevalence rate was found (76%), depression and anxiety being the illnesses encountered. The authors attributed this high psychiatric morbidity to the fact that the migrated patients had been stigmatized and subjected to rejection. Presence of social support (in the form of living in a sheltered supportive environment [ie, "ashram"]), however, contributed to lesser presence of psychiatric morbidity by offering social and emotional security. The authors emphasized the need for focus on other aspects of rehabilitation, apart from vocational rehabilitation. Kopparty and coworkers [33] observed that 20% reported socioeconomic problems, this being 10 times more common in those with deformities. The extent of social problems depended on the degree of visibility and severity of the disease. The most common social problem faced was denial of participation of the family in community affairs. Additionally, they faced avoidance by friends, relatives, and neighbors, and experienced diminished marital prospects. Acceptance was the major coping strategy adopted by those families having deformed patients, whereas avoidance was adopted by those with nondeformed patients. This study demonstrated the social problems (and associated stigma) experienced not only by patients but also their families.

Further addressing this aspect of impact on families, 77 school-going children aged 5 to 15 years and staying in an ashram were examined for any behavioral changes or psychopathology [34]. None, however, manifested with any behavioral changes necessitating a referral to mental health services, indicating a probable protective affect of the ashram and importance of appropriate support and rehabilitation of the leprosy-affected families.

There have been very few studies that have examined the attitudes and knowledge of the patients, families, and the community. In a community study [35] conducted in two different high-prevalence states of India (Andhra Pradesh and Orissa), 1199 community members were assessed on knowledge and attitude related to leprosy. It was seen that a high knowledge level did not necessarily generate positive attitudes. Overall, there was a general negative attitude despite 35% to 50% of respondents demonstrating a high level of knowledge. Segregation from social events and responsibilities, and rejection in marital relationships, were the commonest negative attitudes seen. Bharath and coworkers [24] noted that psychiatric morbidity correlated positively with knowledge about illness and social, emotional, health maladjustment. Nearly two thirds believed that they were being avoided or rejected by their neighbors and the larger society. This perceived social stigma was seen to be influencing their social functioning and psychologic well-being. It has been additionally reported that patients with leprosy can be subject to two kinds of stigma: social stigma and self-stigma leading into socially imposed isolation and self-imposed isolation [36]. In this review, Srinivasan [36] cites a study wherein there was a higher prevalence of self-stigmatization (30%) as compared with social stigmatization (8%) in patients with leprosy-related disabilities. Despite available literature highlighting stigma in leprosy, its related social dimensions are complex, multifaceted, and context-dependent and need to be studied further in greater detail.

Acne is probably the commonest dermatologic disorder and is associated with significant degree of disability and psychosocial distress [37,38]. Its psychosocial aspects have not been reported, however, in Indian literature to date.

In comparative studies on psychiatric morbidity in India, prevalence of depression was 23% and 10% in psoriasis and vitiligo, respectively, in one study [39], whereas another study demonstrated higher psychiatric morbidity (34%) in vitiligo as compared with psoriasis (25%) [15]. Thomas [40] and Bharath [41] did not find any difference in the psychiatric symptomatology and personality profile between patients with leprosy and other skin conditions. Leprosy patients had poorer social adjustment and perceived their neighbors to be rejecting them [41].

## Quality of life

The measurement of the impact of skin diseases on patients' quality of life is important. It is important to be able to measure this effect for clinical, therapeutic, and health service research, for political purposes and potentially to form clinical decisions [42]. The lives of the families of patients with skin disease may be affected. They may experience severe symptoms, especially itch, pain, and discomfort, and can become profoundly psychologically disturbed. Simple aspects of daily living, such as shopping or looking after the home or garden, may become difficult. The choice of clothes may be restricted and these may need to be washed or replaced more frequently. Social activities, such as going out with friends or taking part in sports, swimming, or other physical activities, may become difficult, often because of a reluctance to allow others to see the diseased skin coupled with a fear of what others may think of the appearance. The itch, appearance, or the literal "handicap" of not being able to use the hands at a keyboard because of painful fissures may interfere with work, and the exhaustion of treatment and disturbed-sleep may reduce concentration and make studying difficult. Personal relationships may be difficult to form or may be adversely affected. Their skin disease may also impact their sexual lives. The treatment of skin disease may unfortunately have an initial effect of making quality of life worse because of the difficulty of using topical creams and ointments. To a deeply hurtful extent, ignorant or prejudiced attendants bar many patients with psoriasis and other widespread skin diseases from public swimming baths and patients are excluded from work with the public because employers are concerned about the possible reaction of their customers [42]. A study on people's perception of leprosy noted that people believed that the leprosy-afflicted should stay in leprosy colonies away from the society and most reported reluctance to employ the leprosy-afflicted as domestic help [43]. It is important that stigma issues also be included as an important dimension for quality of life. Evidence of the growing awareness of the value of measuring quality of life in India has been seen in recent publications [44,45]. Prasad and coworkers [17] examined the levels of quality of life impairment of patients with vitiligo. Patients who had successful treatment had a lower impairment of their quality of life than those patients in whom treatment failed.

### Stigma in skin disease: Indian context

Skin diseases are highly prevalent in developing countries like India and failure of display as a result of visibility of skin diseases causes considerable anguish and distress to patients, because society treats them in the same way as anyone else who appears to

be different. Moreover, chronicity of skin disorders punctuated by periods of remissions and exacerbations and associated treatment difficulties can have an adverse impact on various aspects of a person's life (social functioning, school, employment, finances, recreation, and interpersonal relationship). Skin diseases of cosmetic concern like alopecia, melasma, addiviting and exceptional relationship in the singifination properties of self-esteem, embarrassment, and depression.

Stigma about leprosy has been prevalent since ancient times. Stigma about leprosy has four components [46]: (1) physical, (2) psychologic, (3) social, and (4) moral. Leprosy damages skin, face, hands, and feet, which are means of communication, and segregates the patient, because they do not fulfill the identity norms imposed by society [41]. Mhaswade [47] found anxiety and depression in leprosy patients to be related to social variables, such as stigma and ignorance, and reversible with intervention. There are no studies correlating the frequency and nature of psychiatric morbidity to the extent of social stigma, attitude, or knowledge. Knowledge about leprosy among leprosy patients has range from 8% [48] to 93% [41]. Leprosy is associated in minds of many Indian people with beggars. It is not that beggars get leprosy, but that the attendant stigma and consequent unemployment reduces ordinary people to the level of having no alternative but to beg [41]. Leprosy commonly causes physical disabilities, which generate social stigma [49].

There are certain religious or holy cities that used to be the abode of discarded leprosy patients, who had to survive as beggars. Hindu scriptures mention giving alms to such persons as a noble act. Many patients with vitiligo also resort to this because of public misconception of vitiligo as leprosy. Stigmatization by the general public and their negative attitudes toward leprosy negatively impacts on patients' mental health. The patients' perception of the stigma further impacts their mental health [50]. A study on 140 leprosy patients in Bangladesh found depression to be greater in those patients who reported "I have been physically attacked by people," "I feel people regard me as strange," and "I have been refused the purchase of something by a shopkeeper," actual experiences of discrimination based on stigma associated with depression in leprosy patients [50]. VanBrackel [51] conducted a review of literature to examine work done on measuring stigma related to leprosy. Studies that measure stigma were broadly categorized into two groups: studies that assessed the effects of stigma on the person affected, and surveys that assess community attitudes

or practices. In a study of social stigma among leprosy patients [52] attending a leprosy clinic in Gwalior, 26% cases reported social stigma, 43% cases showed social stigma from their neighbors, and 63% cases had stigma for touch. The social stigma was more prevalent in illiterates and low socioeconomic group patients. A total of 69% of cases "were in medu firacial rababilitation, Madies were more victims of social stigma than females. Another study in Nagpur found that women suffered more isolation and rejection from the society [53]. Vlassoff and coworkers [54] reported that although both men and women were negatively affected in terms of their family and marital lives, women suffered more isolation and rejection. Psychologically, women seemed more vulnerable because they were deprived of personal contact with others in the domestic environment where they were accustomed to receiving their greatest emotional rewards. Women reported that indifference to them by other family members, or seeming negation of their presence, caused them the greatest suffering.

Marital relations and occupation have also been reported to be affected by leprosy. In one study [55], 67% attributed leprosy as the only reason for not getting a partner for marriage. Divorcing a leprosyafflicted spouse is one of the manifestations of social stigma attached to leprosy. It mostly depends on the community's decision resulting from the physical and social threat perceived [56]. Leprosy uprooted some patients from their residences, who subsequently settled in a leprosy village or settlement. The occupational status of 46% patients was adversely affected because of leprosy; they became dependents or beggars. The social prejudice and deformities caused by leprosy have played key roles in socioeconomic deterioration of patients. Because of the fear of infecting the family members, women sufferers keep themselves aloof and constantly worry about divorce. Fear of social ostracism prevents the disclosure of disease to the community [25]. Surprisingly, discriminative attitudes were more common in joint than nuclear families. There have been different trends of social problems among the caste groups. Whereas the lower caste groups experienced more severe economic problems, the upper caste groups faced more social problems [57]. The integrated approach to community-based primary health care was found to be effective in reducing leprosy stigma in society [58]. Ironically, the stigma shown toward leprosy was higher among doctors and health educators when compared with the rest of the multidisciplinary team members [59]. Stigma has an impact on decisions to seek help [60]. The review on leprosy-related stigma [51] concluded that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. Despite enormous cultural diversity, the areas of life affected are remarkable similar. They include mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions.

Vitiligo is a common pigmentary disorder of major social and cosmetic concern in India [61]. This disorder does not result in restriction of capacity to work or expectancy of life, but it causes cosmetic disfigurement leading to psychologic trauma to the patients. The reported incidence of vitiligo in various dermatologic clinics in India now varies from 0.5% to 1% [62]. The male/female ratio in vitiligo was observed in this study to be nearly equal, meaning that this disease has no predilection for any sex. Various workers also noted similar observations [63,64]. Further, the incidence of vitiligo was 43% in the 0- to 20-year age group as compared with a low incidence of only 10% in individuals over 40 years of age, which means more young people are getting afflicted with this disorder. Because of social stigma in the community, young women tend to report earlier because of matrimonial anxiety.

## Dealing with social stigma

Irreversible impairments and deformities are the main causes of the complex of negative social reactions attached to leprosy and stigma. Deformities and disabilities led to deterioration in their functional capabilities and their psychologic state of mind [55]. Prevention of disabilities can be achieved by prevention of impairments and disabilities and prevention of worsening of disabilities, but often these do not accompany the services offered toward medical cure at the grass root level [49]. Basic level health workers who have been imparted simple taskoriented training can easily implement self-care learning by leprosy patients and prevention of disabilities services using aids [65]. These services are effective in preventing worsening of deformities of the hands and healing of trophic foot ulcers. The major advantage of such a community-based program is to eliminate the social stigma in the patients' families and the education of the community [49].

Mental health care for patients, regulation of discriminatory action, and education that decreases social stigma among the general population, especially those who might often have contact with leprosy patients, are necessary to improve mental health of leprosy patients [50]. This probably holds

true for many of the dermatologic disorders that are associated with distress, disability, and impaired quality of life. A conceptual issue that needs to be addressed in studies on dermatologic illnesses is "self" versus "social" stigmatization. Studies in general have looked at the self-beliefs, cognitions. and attitudes of the individual in determining stigma. In leprosy, attempts have been made to address the beliefs and attitudes of both patient and society. Stigmatization of persons with leprosy causes the emotional harm of social, economic, and spiritual deprivation. Individual counseling has benefits in addressing these psychosocial problems but is a slow process and effects few people at any one time. Floyd-Richard and Gurung [66] described their experience of group counseling of stigmatized persons, which addressed common issues to more than one person at a time, encouraging the unity of sufferers, developing compassion for others, understanding the common effects of stigmatization, and beginning to overcome its harmful effects. Another important variable to be considered in evaluating stigma is disability and behavior of the individual, which could be seen as being a product of the clinical features of the illness, associated psychologic morbidity, and underlying attitudes. Mahatma Gandhi's contribution in this regard is worth a mention. The Mahatma had a Christ-like compassion for leprosy patients, his approach to leprosy was essentially spiritual, and he included leprosy work as an integral part of his activities [1].

#### Summary

Dermatologic disorders, even though not life threatening, generally have a major impact on patients' daily activities, psychologic and emotional state; and social relationships. The intensity of impact of skin disease on an individual person is extremely variable, however, and depends on the natural history of the disorder; the patient's demographic characteristics, personality, character, and value; the patient's life situation; and the attitudes of society. Social stigma toward dermatologic disorders in the Indian society is quite widespread, especially toward leprosy. The national leprosy control program is quite intensive and addresses comprehensive treatment and medicosurgical facilities for rehabilitation, supporting voluntary agencies working in the field of leprosy welfare and rehabilitation, public education, and mass publicity programs [1]. It is difficult to speculate if this stigma in Indian society is different from other

cultures and societies. Over the years, stigma toward leprosy certainly seems to have reduced. It is evident that this stigma is an important dimension or determinant of quality of life. Dermatologists are expected to consider quality of life issues along with social aspects, nature of disorder, efficacy, and tolerability of various therapeutic options to optimize relief and comfort to their patients.

To get rid of social stigma we have to have self confidence first.

-Cheng Li Wang, China

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