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The Health-Seeking Behavior of Leprosy Patients

An explanatory model

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Abstract

The way people interpret their diseases/illness and its treatment, or the meanings of these, has a direct impact on the way populations at the community and reagional levels deal with their illness as well as the treatments sought and chosen. Our study sets out to assess the socio-demographic profile of leprosy patients and their health-seeking behaviour. We also explore certain cultural factors hallmarking local, traditional remedial choices and as to how this presents an obstacle to effective treatement and consultation. This said, our study further considers how cultural variations lead to interpreting the signs and symptoms of leprosy, that is, to different ways of seeing symptoms and ailments.

Keywords:*Leprosy; health choices; health access; outreach; India*

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1. Introduction

Leprosy, now commonly called Hansen's Disease, has not only been recorded since the era of Great and High Antiquity, sourced in Biblical writings, the classical texts of the Hindus, occasionally featured in Egyptian papyrus and the burden of the returning Crusade of the 9th Century. The origin of leprosy and its early spread, often thought to go back to the Neolithic period, nevertheless remains an enigma for historians tracing the literary and social evolution of this complex, pathological reality. It is difficult to pinpoint precisely where leprosy originated. One view is that it started in Africa spreading very early to India, and consequently, to China. As Scott noted in 1943, the 'study of available records points to its first home being Africa, the belt of land extending across the continent from Nigeria to Abyssenea, the country where the endemicity is greatest today' (Scott 1943, quoted by Dharmendra, 1978). But as Dharmendra remarked: 'a few workers, however, maintain that it might have originated in India and the East, and thus spread from there.' A similar view is expressed by Jopling (1971 cf. Sarkar. 2001:4): 'leprosy is generally believed to have originated in Asia, and the earliest records of leprosy like disease come from China and India of the sixth century BC. And where for Chatterji (1993) India remains the 'Cradle of Leprosy,' for Hastings (1985) it is: '…….Africa may thus vie with India from the unenviable distinction of being the cradle of leprosy'. Certainly, while it may be a perennially difficult task to identify the birthplace of the disease,

Leprosy has been a disease of prevalence since of the dawn of human civilization in India China and Africa (before 600 BC). Yet as George Huntington highlights, in his *The Lazarian Stigma: Leprosy through the Ages*, the equation between leprosy and criminal status (or deviancy) which came to define the social representation of the disease during the Middle-Ages, bore hallmarks of its Biblical condemnation:

> The suffering of the lepers created a problem for philosophers in the Middle Ages. For all intents and purposes, leprosy was a crime. In fact, fake leprosy accusations were often made and had to be settled by the clergy. So how could a kind and forgiving God inflict such suffering? Since leprosy was viewed as divine influence, some viewed it as punishment for sin. King Philip V of France advocated burning alive those affected by leprosy so that their souls and bodies would be purified. The Church believed that leprosy was a kind of purgatory on Earth which would bring a reward in heaven (Huntington, 2012).

Today, however, the diagnosis and treatment of leprosy is easy and most endemic countries are striving to fully integrate leprosy services into existing general health services. Multi Drug Therapy (MDT) was recommended by the WHO Expert Committee in 1984 which in turn published, in 2006, its proceedings from the global forum on leprosy.

Access to information, diagnosis and treatment with MDT (making available Dapsone, Rifampicin, and Clofazimine) remain key elements in the strategy to eliminate the disease as a public health problem, defined as reaching a prevalence of less than 1 leprosy case per 10,000. MDT treatment has been made available by the WHO (the principal donor of MDT medicines) free of charge to all patients worldwide since 1995, and provides a simple yet highly effective cure for all types of leprosy. This is especially important for those under-served, marginalized communities most at risk to leprosy. Supply levels and stock cycles of MDT medicines, remains under the WHO's distribution (from batch testing to shipping).

According to WHO official reports received during 2011 from 130 countries and territories, the global registered prevalence of leprosy at the beginning of 2011 stood at 192,246 cases, while the number of new cases detected during 2010 was 228,474 (excluding the small number of cases in Europe). Most countries that were previously identified as highly endemic for leprosy have since achieved elimination status at the national level and are intensifying their efforts at regional and district levels. Public information campaigns about leprosy in high risk areas are also crucial public awareness mechanisms which can reach out to patients and families, who were otherwise historically ostracized from their communities, encouraging treatment and acceptance. The most effective way of preventing disabilities in leprosy, as well as preventing further transmission of the disease, lies in early diagnosis and treatment with MDT (WHO, 2013).

The year 2011-12 started with 0.83 lakh leprosy cases on record as of 1st April 2011, with PR 0.69/10,000. Up until this date, 32 States/ UTs had attained the status of leprosy elimination. A total of 530 districts (82.8%) out of total 640 districts also achieved elimination by March 2011. A total of 209 high endemic districts were identified for special action during 2011-12 with a total of 1.27 lakh new cases detected. This furnished an Annual New Case Detection Rate (ANCDR) of 10.35 per 100,000, evidencing marginal reduction in the ANCDR of 1.24% from 2010-11 (10.48). 32 States/ UTs had already achieved the level of elimination i.e. with a PR of less than 1 case per 10,000. One State (Chhattisgarh) and One U.T. (Dadra & Nagar Haveli) has remained with a PR between 1 and 3 per 10,000. Bihar, although achieving a PR of <1/10.000 during 2011-12, is yet to be confirmed as an area of elimination and control (NLEP, 2013).

Even to this day, where leprosy is completely curable with MDT (multi drug therapy), some parts of India uphold the belief that leprosy is a divine curse, a punishment of past sins, and a result of immoral sexual behavior. These beliefs reinforce the image of the 'leper' as being physically and morally unclean, to be blamed for contracting the disease and therefore to be socially ostracized. The repulsive physical image, the fear of infection and the belief in incurability are the root causes of the inhuman treatment that is often meted out to those who have leprosy (NLEP, 2013).

The way people interpret diseases/illnesses and the corresponding treatments and meanings of these, impacts on the way illnesses are dealt with and accepted, on both a public and private level. Such meanings and perceptions consequently shape and indeed facilitate public health actions and interventions which are oriented towards illness management behaviour. The understanding of health and illness can indeed vary across different contexts, environments, and cultures, where symptoms of a specific disease can consequently be interpreted differently, nationally, if not regionally so, and what in one culture is interpreted as illness may not be regarded as such in another, for a given disease can change its sense and value according to the psycho-social contexts within which it emerges., When thus considering the cultural variance which defines the complex identity of a country (MacLachlan 1997), perception and intervention can become a cultural, if not public challenge: symptoms of a disease can be ‘culture bound’, where local cosmologies can bring a “twist” to the pathological tale, at times defining the tension between the traditional and modern. What we thus increasingly see, is that maybe we are in fact dealing with a differential paradigm where the human personality, cultural codification, and the socio-economic context of an individual may influence his/her perception of the symptoms and the emotional response towards them (Helman,1994, p107-108). More simply put, two individuals from different cultures or social backgrounds whose biographies have evolved within different contexts and according to different socio-historico-economic variables may interpret the same ‘disease’ or morbid entity (such as tuberculosis) or symptoms (such as pain) *differently*. Cultural variance in the perception of an illness as well as the *ways of seeing* an illness presents the greatest challenge in the delivery of effective health care packages and the promotion of health awareness, nationally and regionally.

The concept of explanatory models can prove useful in exploring both meaning and experience for there is an attempt to understand health, illness, and healing in society, precisely as a cultural system. More specifically, explanatory models are sets of beliefs, knowledge constructs or understandings that specify an illness episode, its cause, chronicity and mode of symptomatic onset; its patho-physiology, course of sickness, and consequent treatment. Such factors are based on the general beliefs which define the “mindset” of a specific culture and their respective behaviors, but differ as to how they are formed and employed to cope with specific health problems. Thus, coping strategies can vary greatly in the way diseases are perceived and treated, and consequently, health-seeking and adherence behaviour varies (Kleinman, 1980).

Angel and Thoits, (1987) for example, present a framework describing the impact of culture not merely on the process of symptom recognition, but upon labelling and help-seeking behavior. They suggest that people inherit from their cultures structured vocabularies of health and illness which limit the possibilities for the interpretation of physical and psychological states and structure help-seeking options/choices. Indeed, concepts of health and illness can be “over-learned”, to the extent that they acquire the status of unquestioned objective reality or become an object of consensus with a specific set of representations. Labels attached to symptoms or illnesses thus influence evaluation and determine the actions taken in response to perceived deviations from physical or emotional normality. Thus the response to a disorder may be dependent on prior evaluation concerning its nature; severity; chronicity; cause; contagiousness; personal responsibility; prognosis; futility etc., with the consequence that people may delay seeking treatment for culturally undesirable disorders.

Health-seeking behavior is a complicated issue, if not a complex paradigm of social, cultural, historical and economic variables defining certain mindsets. Ignorance of general health problems; the lack of awareness of leprosy; socioeconomic limitation; availability and accessibility to health services and stigmatization in the general population may prevent people from seeking help and may indeed prove a barrier to the progressive evolution towards realizing, even in part, successful package delivery and cohesive equity in the most needy of regions and localities. Health service delay can thus also be related to low awareness (or impeded by certain knowledge constructions), and lacking skills of healthcare providers. Identifying *what* people with leprosy think, *why* and *how* they behave will consequently aid program managers design an appropriate community-sensitive intervention strategy, and thus lend such efforts to effective policy design (Zhang S et al, 2009). In a study on health-seeking behavior in two cultural groups for ambiguous symptoms, Karasz and Dempsey (2008) concluded that the relationship between conceptual models of cause and cure depends on the ‘match’ of both to broader, unarticulated cultural models of health and disease. Harju et al (2006) similarly reported that both implicit and explicit attitudes play a key role in deciding when and where to seek medical care.

Although scientific studies, notably efforts through the WHO, have gone some way towards countering the misconceptions, stigma and superstitions attached to leprosy, there nevertheless remains substantial concentrations of community populations, particularly in developing countries, who are yet to adapt their beliefs and attitudes.

Owing to local customs and cosmologies, tradition knowledge construction of disease has meant that reluctance towards modern intervention remains, if not a mistrust towards clinics even after correct diagnosis (Amenu et al, 2000). This in turn increases the trend of risk and an increase in reported deformities which by themselves, bring about medical, social and economic problems for the patients as well as the community. The circle, far from being consistent, is therefore a vicious one where the problems of broken homes and the intense social stigma associated with leprosy create an aura of dread and horror within the local and popular psyche, causing much distress and unhappiness to both patients and their families.

II. Methodology

Our present study seeks to:

- Assert the socio-demographic profile of leprosy patients;
- Assess the health seeking behaviour of leprosy patients;
- Identify and explore factors associated with delays in seeking treatment;
- Study the cultural variations in interpreting the signs and symptoms of leprosy

Through a qualitative methodology we explored the various dimensions impeding proper treatment, access and delivery. Case studies and participant observation were used as a data collection method. The research sample consisted of 195 service users visiting hospitals for treatment and, 50 community sufferers from the *Kushtha Ashram* in Chandigarh. All consenting leprosy patients were at the time attending the Postgraduate Institute of Medical Education and Research (PGIMER), Sector-12 Chandigarh; the Government Multi-Speciality Hospital, Sector-16, Chandigarh, and Poly clinic sector 22, Civil Dispensary, Manimajra. A Socio-economic scale to measure the socioeconomic status of the respondents was also used (Aggarwal et al 2005).

Results

The majority of participants were males (69%) with females representing only 31% of the sample group. The maximum number of respondents (26.5%) was aged between 31 and 40 years. 61% of the respondents were Hindu. The majority of participants were married (76.7%) with 32.7 being illiterate. Only 8% of respondents had attained a higher education qualification (either graduate or post-graduate).

Our socio-economic analysis demonstrated that more than half of the respondents (57.1%) were of poor socio-economic status, 27.8% unemployed. It was found that more than two-thirds (64.4%) of patients had migrated from other states such as Andhra Pradesh; Bihar; Uttar Pradesh; West Bengal; Orissa; Punjab; Himachal Pradesh; Haryana, and Uttaranchal to Chandigarh for treatment and to conceal their disease status.

Variables	**Male (N=169)**		**Female (N=76)**		**Total (N= 245)**	
	Frequency	**% age**	**Frequency**	**% age**	**Frequency**	**% age**
Age composition						

< 20 years	19	11.24	2	2.63	21	08.6
21-30 years	41	24.26	23	30.26	64	26.1
31-40 years	45	26.63	20	26.31	65	26.5
41-50 years	31	18.34	12	15.78	43	17.6
51-60 years	12	07.10	12	15.78	24	09.8
> 60 years	21	12.43	07	09.24	28	11.4
Level of Education						
Illiterate	40	23.67	40	52.63	80	32.7
Up to primary	46	27.22	13	17.11	59	24.1
Matric	33	19.53	8	10.53	41	16.7
High school	35	20.71	10	13.16	45	18.4
Graduation	13	07.69	1	01.31	14	05.7
Postgraduation	02	01.18	4	05.26	06	02.4
Marital status						
Unmarried	031	18.34	13	17.11	044	18.0
Married	134	79.30	54	71.05	188	76.7
Widow	002	01.18	08	10.53	010	04.1
Widower	001	00.59	00	-	001	00.4
Divorced	001	00.59	01	01.31	002	00.8
Occupation						
Govt. Job	10	05.92	00	-	10	04.1
Labourer	59	34.91	05	06.60	64	26.1
Self-employed	14	08.28	04	05.26	18	07.3
Private job	15	08.88	04	05.26	19	07.7
Agriculture	17	10.06	03	03.94	20	08.2
Housewife	02	01.18	44	57.89	46	18.8
Unemployed	52	30.77	16	21.05	68	27.8
Socio-economic status						
Upper high	003	01.78	00	0.00	003	01.2
High	003	01.78	02	2.63	005	02.0
Upper middle	010	05.92	13	17.12	023	09.4
Middle	034	20.11	19	25.00	053	21.6
Poor	106	62.72	34	44.73	140	57.2
Very poor/BPL	013	07.69	08	10.52	021	08.6

Socio-demographic characteristics of respondents

The level of deformity of the leprosy patients demonstrated that 31.4%, 32.2% and 36.3% had primary, secondary and no deformity, respectively. The symptoms for primary deformity comprised of anaesthesia and for the secondary deformity, the symptoms were occurrence of ulcers and loss of digits. 36.3% had already completed the prescribed course of treatment. It was found that 56.17% and 43.83% of those who had completed their treatment, availed treatment services before and after the advent of MDT, respectively. The remaining 63.7% of the respondents were still undergoing medical treatment for the disease.

III. Perception and Treatment

Our present study documents the way people interpret their disease and its treatment, that is *ways of seeing and ways of acting* The illness behaviour of the respondents is aimed at getting a handle on community awareness level; the way manifest personal concern; the treatment strategies they consequently follow; how and why they comply with these treatment strategies; and finally the influence of socio-cultural and socio-economic factors. In the context of the present study, the illness behaviour of leprosy patients were divided into six major categories: a) appearance of symptoms; b) diagnosis of symptoms; c) consultation sought from a health care provider [quacks-*desi* healers; tantrik-occult practitioner, and medical specialist]; d) treatment experience; e) outcome of treatment and f) satisfaction with treatment.

One of the major findings that appeared during our analysis was the way people interpreted their symptoms of leprosy and as to how perception influenced respective health-seeking behaviors and knowledges. Doctor were found to be the sole source of information for all respondents and key actors in the promotion of awareness for it was also observed that leprosy was misunderstood as other ailments depending upon its physical manifestation. The level of awareness among all respondents with regard to the initial symptoms of leprosy was found to be alarmingly low at 2.4%. Due to variance in the physical appearance of leprosy from person to person, respondents were not able to identify the initial symptoms through a common comparative measure.

The respondents, furthermore, believed that leprosy was only a disease of deformity i.e. it led to disfiguration or bodily deformation. A number of the leprosy patients were suffering from numbness while those who had contracted leprosy at more advanced ages had developed pale patches on their body parts. It was also reported that there was an appearance of skin lesions such as ring worm, rashes, skin eruptions or allergic reactions. They misinterpreted these skin lesions as mere skin infections. 68.2% of respondents related their initial symptoms with *sunpan* (sensory loss*)*, 58.0% to *safed nissan* (white patches) which generally did not increase in size and were dry; 18% stated papules nodules; and 15.5%, 9.8 % and 6.1 % described *kushki* (dry skin), annular lesions and maculae, respectively.

Nearly half of the respondents (49.7%) respondents were unaware of the severity of symptoms such as red patches, minor swelling, tingling sensations felt in wounds, believing that the symptoms would disappear

As reported earlier, two-thirds of the respondents had migrated from the other states. The socio-cultural norms vary from state to state, so as the mindset of the respondents belonging to them. The respondents from the states of Punjab and Haryana believed that white patches were very common in the rural areas and prevalent in children too. These patches reduce in size as the child grows. Whereas respondents from Uttar Pradesh, Bihar and Madhya Pradesh believed that the white patches develop due to askin or blood infection.

Another ubiquitous confusion was noted with regard to the terms *Kodh* and *Kustha*. Technically speaking, these two words are one and the same substantive. According to the respondents, *Kodh* was incurable; it is a disease of sin and afflicts those who have accrued misdeed in their past or present life. *Kustha* on the other hand, is curable and nothing more than a simple skin disease. As one respondent narrated:

> Sahab muje to kuhstha rog hai, muje kodh kyon hoga. Maine kabhi bhi koi bura kaam nahi kiya. kodh to un logo ko hota hai jinhone pichale janam mein koi bura kaam kiya hota hai. Bhagwan unko unke bure kamo ki saza kodh ke roop me deta hai.
> (Sir, I am suffering from Kushtha Rog, Why would I get Kodh? I have never committed any wrong deed. Leprosy occurs to those who had committed wrong deeds in a past life. God punishes them for their deeds in a form of kodh/leprosy.)

However, leprosy and *Kustha rog* are one and the same entity. The symptoms in the first stage are patches, an initial numbness or slight swelling. Characteristic of this stage is the absence of active health seeking behaviour. In case the symptoms manifested in forms of wounds and boils, the respondent sought help of local healer or Registered Medical Practitioner (RMP) otherwise home remedies was the first preference. The spreading of patches, numbness and at times outbreaks of blisters were characteristics of the second stage. At this stage, the respondent or their family members discussed the illness among themselves or with their close relatives. If they believed symptoms to be indicative of infection or snake bite, they were likely to consult a local healer or RMP doctor. In case these symptoms were accompanied by lived misfortune, family members sought the aid and counsel of traditional practitioners.

The third stage of leprosy is when the body part, especially the finger/toe, evidence disintegration where the respondent did obtain relief neither from the traditional healer nor from the RMP doctor. In these cases, it was on the advice of family members that the patient visited the government leprosy clinic.

Another important observation of our study was that all respondents had shared and discussed their symptoms with family members, friends or relatives. What needs to be stressed at this juncture is a critical behavioural response provided by familial and community contexts. In the majority of cases, the remedy suggested by such groups was traditional in nature that is folk wisdoms - varying from oil massage to the use of herbal concoctions and applications of paste based creams. Aside from a small number of participants (6.93%) respondents who were educated and aware of the disease, the majority of respondents sought clinical treatment. One of the respondents narrated as follows

> Maine apne safed daag ke bare me apne parivar ko bataya to unhone muje kaha ki ye nishan to garmi ke karan ho jate hai. Tel ki maalish karne se apne aap thik ho jayenge
>
> (When I discussed about the white patches with my family, they told me that these patches have occurred due to hot weather. They suggested I massage them with mustard oil.)

In another instance, few respondents reported numbness in their hands and feet and when discussed with family members, alternative explanations were given. As narrated by one respondent during the interview

> Ek din khet mein kaam karte hue achaanak muje aisa laga ke meri pakadne ke takat kamzor ho gyi hai. Mein kuch bhi apne hath se pakadta tha, vo haath se chut jata tha. Maine ye baat apne dost ko batayi. Usne muje bataya ki ye sab to nason ke dabne se ho jata hai. Haldi or sarson ke tel ki malish karne se do-tin din me ye samasya apne aap thik ho jaygegi.
>
> (One day while working in the fields, I suddenly realized that my grip had weakened. Whatever I held just fell from my hand. I informed my friend about it. He told me that it was due to the

> pressing of nerves and that the problem would be solved by massaging with turmeric and mustard oil paste for 2-3 days.)

Believing such suggestions and folk remedies, respondents ignored the primary and secondary symptoms, which resulted in the full onset of disease and its consequences of deformity. Consultation with local *desi* doctors was initiated on noticing the enlargement of small patches, and conversion of a small cut into a wound. Otherwise, they would resort only to self-medication or home remedies. In some cases, respondents related symptoms such as facial swelling, nodules on ear through sorcery and black magic. Accordingly, they thought that traditional healers alone in the treatment of the symptoms. Only a small number of respondents (6.93 %) took initiative and sought treatment from a medical practitioner in the initial stages of disease (Fig.1).

While discussing experience related to the treatment of respondents, it was observed that ignorance about symptoms led to the transformation of a small patch/ cut into deformation of various body parts. The patient went through various modes of treatment beginning with home remedies such as oil massage to reconstructive surgery.

In the present study, the majority (26.93%) of respondents reported that during the initial stages of their disease, self-medication such as massaging with mustard oil was sought, as was treatment with some *desi-jadi butti.* Finding the respective method ineffective against the diagnosed symptoms, to the advice of a community *desi* doctor (quacks) was sought. This entire process took 4-5 months.

Respondents reported that due to numbness caused by the disease, they ignored the painless patch or wound. When the local *desi* doctors also failed to provide effective treatment, the respondents resorted to traditional healers who provided the respondents with herbal medicines, holy water, and herbal paste. The belief was that primary symptoms amounted to nothing more than a skin infection, with 34.28% of patients first seeking relief through non-prescribed medication obtained from a local chemist or Registered Medical Practitioner (RMP). According to the respondents, medicines like avil, cetirizine etc were usually taken through self initiative without seeking the counsel of the familial and community circle. The government hospital was approached only when the over-the-counter medicines failed to curb the intensity of pain. Only 6.93% of the respondents approached a skin hospital without practicing any home remedies and in many cases, respondents approached skin departments after having “done the rounds” at other departments such as medicine, neurology, etc.,. Failure to identify the primary symptoms through the lack of proper diagnosis meant that doctors often undertook various medical tests which were not failed to identify leprosy. The experience of the respondents at secondary level hospital services depicted that doctors initially diagnosed respondents with nerve affectations and prescribed a 3-4 month treatment with further tests recommended. Only when the requested course of treatment failed to provide relief, did the doctor subsequently see fit to refer patients to a skin OPD, wherein a full diagnosis was provided Realizing the ineffectiveness of traditional treatments, respondents sought biomedical treatment either from private or government leprosy control programmes. Although all respondents were aware of the effectiveness of biomedical treatment a certain number (31.83%) held a strong belief in the traditional medical system. Only those respondents who suspected that they could have leprosy sought treatment from biomedical practitioners. Otherwise, the prevailing belief system among many respondents was that leprosy was a disease of sin, and only a sinner could be infected as a result of misdeeds in the past or present life. This belief was so firmly established in their mindset that the thought of leprosy was a far flung possibility obscured by habitual beliefs.

IV. Discussion

We attempted to construct and verify a decision making process describing the health seeking behaviours of respondents by considering the following questions:

- What types of health seeking behaviors does a person infected with leprosy adopt in order to obtain an accurate diagnosis and treatment once they have accepted their symptoms, and how long is the delay for treatment before they finally visit a doctor?
- How does a leprosy sufferer choose a course of treatment?
- What are the decision-making strategies used by a leprosy patient when visiting a doctor or when using alternative treatments such as traditional healing, faith healing, etc.?

Such factors influence decision making and result in a lengthy gap between the appearances of primary symptoms to the initiation of treatment. The reason for such a detrimental delay between the onset and an initial visit to the doctor is not only the habitual perception of symptoms as something other than what they actually are, but also the very real geographic and socio-economic barriers which exist such as the socio-financial status of the respondent, travelling distance to health care facilities, and the level of health concern. Respondents were asked to identify the main causes for such delays. 64.0% of the respondents attributed their delay to a general lack of awareness, as one respondent described:

> Maine kabhi leprosy ke baare me nahi suna tha aur na hi main iske baare me janta hun ki ye kaun si bimari hai. Main to doctor ke paas isliye aaya tha ki muje pata chal sake ki ye lal rang ka nishan mere shareer par kyon ho gaya hai or iski davai lene aya tha.
>
> (I had neither heard about leprosy nor did I know what type of disease it actually is. I visited a doctor for knowledge and treatment of the red patches that developed on my body.)

When the same question was posed to staff members of a leprosy clinic, they stated the main reasons behind such a delay are ignorance, absence of pain, general disinterestedness, and the denial that leprosy could not possibly befall them. Certain respondents stated that they had been misguided by traditional healers:

> Maine baba ki davai par pura vishvas kiya. Jo baba ne kaha main vo maanta raha, us samay muje kuch bhi samaj mein nahi aa raha tha ke muje kya karna hai.
>
> (I fully trusted the medicines of Baba. Whatever Baba said, I adhered to it. At that time, I was not able to understand what I should do.)

Respondents who had migrated from other villages reported that doctors in their areas did not have proper knowledge about leprosy and there was a general lack of awareness with regard to the exact cause and symptoms of the disease. One of the respondents stated that he had asked RMP numbers, without satisfactory answers in return, believing it to be a standard skin irritation. But there is also the fear of leprosy: many reject an early diagnosis fearing not just the physical, but the social and community consequences of such a disease i.e. fear of rejection and isolation from peers, and shame. Such fears and pressures lead to the initial denial of diagnosis within already stretched territorial services. Thus, Cost, fear of diagnosis, territorial access, and uncertainty about treatment delays access to treatment.

Most leprosy cases do not have disabilities at the onset of disease. Many conditions leading to disability and deformity can be curtailed if preventive action is taken at an early stage (Srinivasan, 1993). Where other studies have confirmed that the delay in diagnosis increases the rate of disability, (Meima et al, 1999 & Deps et al, 2006) our research suggests that disability onset is closely associated with patterns of health knowledge and health seeking behavior. Samraj et al 2012, for example, have found that most patients ignore early leprosy symptoms due to their painless, quiescent nature and seek help only with the onset of visible or bothersome complaints where 53.5% of participants identified a "red patch" as the primary symptom. Other study populations have reported tingling sensation/numbness preceding the patch and this may be indeed regarded as an early symptom of Leprosy (Zhang, 2009). Respondents experiencing symptoms of a disease but not unaware of their health status followed different modes of personal enquiry. A shift from the denial to acceptance of leprosy and the seeking of treatment has been observed. Few respondents failed to take any measures on the appearance of symptoms, and where some resorted to over-the-counter medication, others followed folk remedies or visited health care facility treatment. When illness behavior is recognised medically and a role model of a patient is established, it is referred as a 'patient's role'. The manifestation of such roles varied depending upon the social and community expectations of the patient. The respondents developed perceptions and judgements about symptoms after experiencing physical discomfort. This discomfort was followed by adopting appropriate measures, namely health seeking behaviour.

Many personal and social factors have an impact on a patient's decision to seek health care. These factors may interact and may differ among different study populations and from person to person. It is apparent that many patients did not regard their symptoms as severe and nothing more than a skin irritation (Heijnders, 2004). In Thailand similarly highlight that the response to illness differs according to demographic and personal factors, to physical and social factors, and to illness-related factors, specifically pain, disfigurement and stigma. Leprosy was perceived and experienced as a series of acute disorders not necessarily related to one another (Neylan et al, 1988).

Non-compliance with leprosy treatment was influenced by various socio-cultural factors such as social networks, gender, economic status, knowledge and duration of sickness, the patient's judgment of the extent of sickness, accessibility to health facilities, and the anticipated cost of treatment. Distance, most tellingly, has been found to be one of the factors influencing health service utilization in the study of H. Kloos (1990) re-emphasizing the need for improvements in health infrastructure, which would in turn, improve territorial access to leprosy services. Most individuals attributed the aetiology of the disease to supernatural or 'other-worldly causes' such as retributive action of past sins. Given that it is not unusual for patients to leave home for fear of losing family prestige or to avoid hated of other family members; one of the reasons for irregular attendance at hospitals was precisely to avoid being identified as leprosy sufferers. There are also lingering myths which need to still be tackled and dispelled: the association of leprosy with chronic deformity; the fear for patient's children; the belief among communities that it is necessary to segregate. Denial, in cases of severe stigma further enhance the likelihood of forced redundancy and failed marriage prospects, not just for the sufferer but for distant relatives. This said, leprosy continues to be associated with significant stigma among communities, this further translating into the delay in seeking appropriate treatment, adversely affecting care seeking habits (Nicholls et al, 2003). So much so is the psychological reality of such disease a key concern, that in India, Bharath et al, 2001 have shown an association with psychiatric morbidity. In South Africa, Scott (2000) reported that responses to leprosy diagnosis included feelings of rejection, worthlessness, guilt, confusion, fear, grief and anger, with 11 of 30 patients interviewed reporting suicidal thoughts. In Brazil, De Oliveira, 1990 reported the response to diagnosis to include fear, disgust, loneliness, grief, aggressiveness, anger, family and social rejection. Such research evidences, that above and beyond the clinical tableaux of disease, there is the social reality of the disease, which policy design has to take into account with the view to creating effective tools for public knowledge enhancement, and curtailing one of the principal factors in the delay and access to effective health care provision.

Spiritual and traditional healers are often the first resort rather than modern medicine. In the present study, leprosy patients are seen to resort to various modes of treatment such as traditional healing, faith healing, ayurvedic treatment and biomedical treatment. Similar results have also been found in various other studies which support this finding of the present research work that the traditional beliefs and health-related practices have the potential to add to delay. The infection as a cause of leprosy was recognized by only 3.57% patients whilst the majority had little consciousness of its aetiology (70.24%) or thought it to be due to punishment for past sins (3.57%) or due to supernatural causation (1.19%). Most of the participants (70.2%) left home for fear of losing family prestige, in order to hide the disease (25.00%) or due to the hatred of other family members (4.76%) (Vyas et al, 1982). Denial was found to be an understandable coping mechanism in view of the severe stigma associated with leprosy. The presence of close-knit extended families, in which joint decision-making was the norm and in which such a dreaded diagnosis could spell the end of job and marriage prospects for even distant relatives, contributed to the likelihood of denial.

The traditional healer is both part and parcel of the social milieu within which he commands respect. Considering the present manpower in the National Leprosy Control Programme, such community actors can be considered a boost to numbers. In addition, the negative aspects of health care as practised by many practitioners could also be corrected by appropriate training and consistent, regular guidance (Kaur et al 1984).

Our study also shows that many patients had initially consulted traditional healers, inadequately-trained physicians, and/or untrained medical practitioners for treatment of their symptoms, which resulted in lengthy delays before correct diagnosis. Further, even after the diagnosis was made and appropriate medications were prescribed by trained personnel, most patients were not told what had caused their leprosy and as to how the drug regimen worked to combat it (Mull et al 1989). Leprosy sufferers recognized by the community had visible signs such as wounds, swellings and deformed feet or hands – motives for negative community perception understanding such “signs” as “curses.” This signals that leprosy remains more than a disease: it can be medically cured, but the social sickness of leprosy still remains (Stigter, et al 2000). Thus there is a delay of months and even years before public health facilities are accessed – there are the community, social and psychological barriers to be overcome in the first instance. Distance was not regarded as a problem, because most patients went to nearby district hospitals. In district hospitals, misdiagnosis was still common. More than half of leprosy patients said that they did not receive any information about leprosy before they were diagnosed. Travel costs seem to cause problems for poor and aged patients. Patients at district and provincial hospitals complained that the waiting times to consult staff were too long. In most health facilities, privacy during examinations was not adequate. Patients placed a priority on health staff being friendly and respectful to them (Kampirapap et al, 2005).

Traditional beliefs are found to affect health seeking behaviour leprosy sufferers. We have home-spun philosophies of diseases, for instance where a rapid change from hot to cold affects health or that the onset of the winter season in India(August) causes the blood in the entire body change, making people susceptible to disease. Local people believe that this notion holds true for the death rate is seasonally high. Traditional beliefs persist that health, remains a matter for God, and that the individual does not have control over the maintenance of his/her health, or more precisely, over his/her wellbeing. It is the blessings from God that sustain health, and if disease should arise, it is either witchcraft in the form of a curse or the store of a sinful past unleashing itself. In this context, seeking any form of treatment is considered inappropriate or inadequate. The decision making strategies underlying health seeking behaviour and the use of various modes of treatment by the leprosy patients, must be researched to a greater extent. This is especially important in India where there is a twofold system of modern and traditional medicine prevailing in addition to a variety of folk remedies. In order for leprosy sufferers to receive optimal medical services and to ensure the effective utilisation of medical services in such an environment, it is necessary to first understand the health seeking behaviour of the respective patient and the community within which he/she has grown, psychologically developed, and taken life choices through the values systems created therein.

References

Aggarwal, O. P., Bhasin, S. K., Sharma, A. K., Chhabra, P., Aggarwal, K., and Rajoura, O. P. (2005). A New Instrument (Scale) For Measuring The Socio-Economic Status of A Family: Preliminary Study. Indian Journal of Community Medicine, 30(4), 111-114.

Amenu A., Nash J., Tamiru T. and Byass P. (2000). Patterns of health-seeking behavior amongst leprosy. *Ethiop. J. Health Dev*., 14(1): 43-47.

Angel R and Thoits P. (1987). The impact of culture on the cognitive structure of illness. *Culture, Medicine and Psychiatry*, 11:465-494.

Bharath S et al. (2001). Correlates of psychiatric morbidity in patients with leprosy. *Indian Journal of Leprosy*, 73(3):217-288

Chatterji, B.R. (1993). *Leprosy-etibiology of manifestation, treatment and control*. District Purulia, West Bengal, Jhalda -723002.

De Oliveira M. (1990). Emotional reactions of hanseniasis patients with physical deformities. *Hansenologia Internationalis*, 15:16-23.

Deps PD, Guedes BVS, Filho JB et al. (2006). Delay in the diagnosis of leprosy in the Metropolitan Region of Victoris, Brazil. *Lepr Rev* 77: 41–47.

Dharmendra, N.S. (1978). History of spread and decline of leprosy. In *Leprosy*, ed. Dharmendra, 1-21. Bombay : Kothari Medical Publications.

Harju BL, Wuensch KL, Kuhl EA et al (2006). Comparison of rural and urban residents' implicit and explicit attitudes related to seeking medical care. *J Rural Health.* 22: 359-363.

Heijnders ML. (2004). Experiencing leprosy: perceiving and coping with leprosy and its treatment. A qualitative study conducted in Nepal. *Lepr Rev* 75: 327–337.

Helman CG. (1994). *Culture, health and illness*. An introduction for health professionals. Butterworth-Heinemann, Oxford 107–108.

Huntington, G. (2012). *The Lazarian Stigma: Leprosy through the Ages*. http://newhistories.group.shef.ac.uk/wordpress/wordpress/?p=3032. Accessed 12/12/2012

Kampirapap, K., J. Vorasayan, S. Poopook, and S. Kachen (2005). Assessment of the quality of leprosy services from the clients' perspective in Thailand. *Leprosy Review* 76:325-334.

Karasz A and Dempsey K (2008). Health seeking for ambiguous symptoms in two cultural groups: A comparative study. *Transcult Psychiat.* 45:415-438.

Kaur, P., U.C. Sharma, S.S. Pandey, and G.Singh (1984). Leprosy care through traditional healers. *Leprosy Review*

55:57-61.

Kleinman, A.(1980). *Patients and healer in contexts of culture*. Berkeley: University of California Press.

Kloos, H. (1990). Utilization of selected hospitals, health centers and health stations in central, southern and western Ethiopia. *Soc. Sci. Med.* 31(2): 101-114.

MacLachlan M. (1997). *Culture and health.* Trinity College, Wiley, Dublin.

Meima A, Richardus PR, Gebre S et al (1999). Factors associated with impairments in new leprosy patients: the AMFES cohort. *Lepr Review* 70: 189–203.

Mull,J.D., C.S.Wood, Lydia P.Gans, and D.S.Mull (1989). Culture and compliance among leprosy patients in Pakistan. *Social Science and Medicine* 29(7):799-811.

National Leprosy Eradication Programme (NLEP) (2013). http://nlep.nic.in/stigma.html. Accessed 16/3/2013.

National Leprosy Eradication Programme (NLEP) (2013). http://nlep.nic.in/data.html. Accessed 16/3/2013.

Neylan TC et al. (1988). Illness beliefs of leprosy patients: use of medical anthropology in clinical practice. *International Journal of Leprosy & Other Mycobacterial Diseases*, 56(2):231-237.

Nicholls P G, Wiens C and Smith WC (2003). Delay in presentation in the context of local knowledge and attitude towards leprosy—the results of qualitative fieldwork in Paraguay. *Int J Lepr Other Mycobact Dis.* 71: 198-209.

Samraj, A, Kaki S, Rao PSS (2012). Help-Seeking habits of untreated leprosy patients reporting to a referral hospital in Uttar Pradesh, India. *Indian J Lepr* 84:123-129.

Sarkar, P. (2001). .*Leprosy in the new millennium*. Wardha: Gandhi Memorial Leprosy Foundation.

Scott J. (2000). The psychosocial needs of leprosy patients. *Leprosy Review*, 71(4):486-91.

Srinivasan, H. (1993). Prevention of disabilities in patients with leprosy. WHO.

Stigter, D.H., L. De Geus, and M.L.Heynders (2000). Leprosy: Between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Leprosy Review* 71:492-498.

Vyas, G.K., I.U.Dudani, and R.C. Chaudhary (1982). A sociological study of leprosy cases in the Gandhi Kusth Ashram, Jodhpur (Rajasthan). *Indian Journal of Leprosy* 54(2):324-331.

WHO (2013). Leprosy elimination; Leprosy Today http://www.who.int/lep/en/. Accessed 16/3/2013.

Zhang F, Chen S, Sun Y and Chu T. (2009). Healthcare seeking behavior and delay in diagnosis of leprosy in a low endemic area of China. *Leprosy Review* 80, 416-423.