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Original Article

A Glimpse of Present Day Perspectives of Stigma Associated with Leprosy : A Qualitative Study from a Tertiary Care Centre in Tezpur area of Assam, India

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Since time immemorial, Leprosy is linked with stigma and discrimination mainly due to lack of proper knowledge and understanding of the disease. The attitude and beliefs of people and society add to the preexisting situation(s). This affects the status of individual in society, social and occupational life. As social beliefs change with the time and vary from area to area, this study has been carried out to understand the present-day perspectives of stigma associated with leprosy Assam and its impact among patients of leprosy and community members. Specifically, this study aims at understanding as how the gender relations affect access to resources, decision making, and division of labour in patients of leprosy. This qualitative study has been conducted in a Tertiary Care Centre in Tezpur area of Sonitpur district of Assam, a state of Northeast India, to explore the present-day perspective of leprosy affected individuals and society towards the disease particularly the impact of leprosy on the patients' mental health, marriage, social interaction, and employment. Data was collected through 6 focused group discussions including 90 participants (24 patients of leprosy receiving treatment from the hospital. The other respondents were non leprosy patients which included 42 family members, 16 colleagues, 8 health care workers), in–depth interviews and questionnaires involving the patients of leprosy and their close family members being attended at this centre. It was observed that the family members especially first-degree relatives and spouses had a major role tackling situations arising out of social stigma of the disease specially in patients dealing with reactions and deformity. Hospital staff were largely found to have a positive outlook on the disease process and evolution. There was no stigma or discrimination attached with delivery of health care services in our study. Our study also provides an overview of the impact of leprosy on the mental health on the patients and family members due to disease, reactions and deformities.

Keywords : Leprosy, Stigma, Deformity, Reactions, Marriage, Social Interaction, Employment, Northeast India.

Introduction

The history of one of the oldest diseases of mankind, leprosy can be traced back to thousands of years. First mention of the disease is available in an Egyptian Papyrus document dated around 1550 B.C (Sermrittirong & van Brakel 2014). The stigma of the disease is very deep rooted in families and communities. Communities from Nepal and Indonesia believed that the disease is a result of will of God and punishment from God (Brown 2006, Try 2006). Leprosy presents early in the form of painless hypopigmented anesthetic

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lesions over body which when left untreated progress to cause destructive and irreversible damage to skin, nerves, eyes, and body parts. Anesthetic deformities develop into ulcers which gradually incapacitates the individual of carrying out essential daily activities (Lockwood & Suneetha 2005).

Scambler (2004) elaborated and differentiated between perceived (felt) stigma and enacted (behavior) stigma. Enacted stigma restricts the participation of the affected persons in routine activities by family, colleagues, and society generally. Perceived stigma causes the psychological distress and affects the attitude of the affected individual (Weiss et al 2006, Scambler 2004).

The definition of stigma was first given in 1963 by Goffman where he defined stigma as "spoiled identity". The individuals were classified into three categories (Goffman 1963):

1) "Stigmatized" are those who are ostracized, devalued, rejected, scorned, or shunned; they experience discrimination, insults, and attacks, and are even murdered.
2) "Normals" are those who do not bear the stigma.
3) "Wise" are those among the normals who are accepted by the stigmatized as "wise" to their condition.

Stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem (Weiss et al 2006).

Our study provides a glimpse of the present-day perspective of leprostigma- stigma associated with leprosy, among patients and the community members who are associated with them through blood or social ties. The study has been carried out in Tezpur area of Assam. To date no major study has been reported to our knowledge from the state of Assam and hence the current issues being faced with reference to leprosy stigma in specific study area or similar areas of Assam could not be commented upon. In the present study we endeavor to bring out the problem statement which includes gender determinants, social behavior, mental health of leprosy affected patients and its probable solutions.

Broad objective of the study is to assess the knowledge, attitudes, beliefs of leprosy patients receiving treatment from the hospital and their close circle of friends, family and colleagues.

Specific objectives include studying the role of family members in leprostigma and how the gender relations affect access to resources, decision making, and division of labour in patients of leprosy, understand the quality of health services and access to resources for patients of leprosy, studying the social behavior and role of society towards the disease by focusing on social events like marriages, birth, death rituals, use of public transport like bus, trains, aircrafts, behavior at workplaces, behavior at public places and places of recreation like hotel, restaurants and impact of leprosy on the patients' mental health.

Material and Methods

This is a cross-sectional prospective study conducted in Tertiary Care Hospital of Tezpur area of Assam. Tezpur area comes under district Sonitpur of the state of Assam. As per the leprosy data from Sonitpur district of Assam, 44 cases were reported for the year 2022 which included 19 new cases of multibacillary leprosy and 4 cases of paucibacillary. There were 3 cases of childhood leprosy. Three patients had grade 2 disability. The ANCDR of the district was 1.13/1,00000 population. 19 cases were found to be defaulters and were restarted on treatment again.

The study was conducted for a duration of six months from Aug 2022 to Jan 2023. Data was collected in these months through personal and telephonic interviews and questionnaires. Complete data was tabulated and analyzed during February and March 2023.

Study population:

The study population comprised of patients taking active leprosy treatment from the hospital, their family members, first degree relatives - father, mother, son(s) and daughter(s) who were requested to visit with the patient in hospital at the time of medicine collection. Other participants interviewed included spouses, colleagues, subordinates at work and health care providers like doctors, nurses, paramedics, physiotherapists. This study was conducted with due approval of the Institutional Ethics Committee.

Methods of data collection:

To achieve broad and specific objectives various data collection tools were devised which included,

(i) In-depth interviewing of leprosy patients.
(ii) Administering a formulated questionnaire to patients of leprosy and their family members.
(iii) Interviewing medical staff.
(iv) Interviewing paramedical staff.
(v) Interviewing physiotherapist in the hospital.
(vi) Interviewing family members.
(vii) Conducting focused group discussions (FGDs) on specific topics which included the specific objectives.

A total of 6 focused groups were formed comprising of similar participants in each group on different days. The group participants were similar in age, gender, socioeconomic status, education, cognitive structures, beliefs, and perception of their social environment. Each session lasted for 45 min to one hour in the presence of a moderator who was also a flexible interviewer guide. The interviews in focused groups were open-ended to promote discussions between participants on specific topics. The interviews were recorded in audio tapes. Notes were also taken down in pen and paper by the data collector.

The study participants were thoroughly explained about the aim of the study. A thorough pilot tested, and formative questionnaire guide was prepared by the researcher for the interviews (Fig.1 - Questionnaire).

The interviews were recorded in local language and translated verbatim in Hindi and English. The participants were also interviewed by a second researcher independently to overcome the discrepancies and to enhance the validity of the findings. The recorded data was shown to participants again for assessing and removing the inconsistencies in paraphrasing and comprehension of the interviewer. The information collected was translated and transcribed to written text line by line in Microsoft office. Codes were generated using an inductive approach which were further categorized into bullet points categories. Broad themes were formed by the researcher and investigator. Data was analyzed separately by researcher and investigator and was collaborated jointly after discussion. To ensure rigor of the study factors like credibility, dependability and conformability were taken into special consideration through in-depth, meticulous data collection and by rechecking the data summary by the participants.

Sample size:

The sample size of the study consisted of 24 patients of leprosy receiving treatment from the hospital. The other respondents were non leprosy patients which included 42 family members, 16 colleagues, 8 health care workers (2 doctors 2 paramedics 2 nursing assistants and 2 physiotherapists (Table 1).

d. **Criteria for selection of respondents**: 24 patients of leprosy receiving MDT from the

- What does stigma mean to you?
- Are you familiar with the concept of leprosy? If yes, what information or beliefs do you associate with leprosy within the Indian diaspora?
- How do you perceive individuals with leprosy within the Indian diaspora? Please describe any stereotypes or misconceptions you may have encountered.
- In your experience, what are the main factors that contribute to the stigma surrounding leprosy within the
- How do you think the stigma of leprosy affects the lives of individuals within the Indian diaspora who have been diagnosed with the disease?
- What role do you believe cultural beliefs and practices play in perpetuating the stigma associated with leprosy within the Indian diaspora? Please elaborate.
- Are there any specific cultural or religious perspectives within the Indian diaspora that influence attitudes and perceptions towards leprosy? If yes, please describe.
- How can education and awareness be effectively utilized within the Indian diaspora to combat the stigma associated with leprosy? What methods or platforms would be most effective in disseminating accurate information?
- In your opinion, what steps can be taken within the Indian diaspora community, both locally and globally, to challenge the stigma of leprosy and promote inclusivity and acceptance of individuals affected by the disease?

Fig. 1 : Questionnaire administered to patients of leprosy and non-leprosy responders.

past one year were included in the study. The other respondents were family members colleagues and health care workers of the hospital.

e. **Inclusion criteria**: Patients of leprosy on MB-MDT, family members of patients, health care workers from hospital, participants giving consent to be included in study.

f. **Exclusion criteria**: Those who were not willing to participate were excluded.

g. **Data analysis**: The questionnaires used in the study were designed for qualitative output. The data collected was analyzed qualitatively.

Results

Profile of participants is summarized in Table 2.

Of the 24 patients of leprosy in the study in the age group of 15 to 65 years, 4 patients were in the age group of 15-30 years, 10 in 31-45 years, 10 in 41 to 65 years age group. 16(66.66%) were males and 8 (33.33%) were females. All these patients were continuing standard MB-MDT. 4(16.66%) patients had deformities in the form of clawing of digits and foot drop. These patients were undergoing physiotherapy sessions in the hospital and using splints for clawing of digits. One patient had active leg ulcer who was undergoing regular silver dressings and weekly local infiltration of platelet rich plasma in the ulcer. Two patients were in type 2 reaction being treated with tablet thalidomide along with MB-MDT and 1 patient had type 1 reaction who was taking tapering doses of oral steroids and MB-MDT.

The participants included 24 patients of leprosy and out of which 16 were male patients were employed (3 retired) and 8 female patients were housewives. Other study participants included 42 family members, 16 colleagues and 8 health

Table 1 : Sample size with reference to each set of data collected from respondents.

	Objectives	Data collection tools/ methods used	Respondents	Sample size
1.	Study of knowledge, attitude and beliefs of patient and society	In–depth face to face interview	Leprosy patients, family members and health care workers	64
2.	Role of family members, gender relations in decision making	In depth telephonic interviews	Colleagues.	16
3.	Quality of health services and access to resources	Questionnaires	Leprosy patients and family members	66
4.	Social behaviours	Questionnaires	Leprosy patients and family members	66
	Mental health, Marriage, Social interaction, Employment	Patient questionnaires and in-depth face to face and telephonic interviews	Leprosy and non-leprosy responders	
		FGD1	15	
		FGD2	15	
		FGD3	15	
		FGD4	15	
		FGD5	15	
		FGD6	15	
	TOTAL SAMPLE		90	

care professionals were essentially qualified.

In-depth interviews of the participants belonging to the age group of 15 to 65 years were conducted. Six themes were generated from the verbatim in- depth interviews of the study participants about topics like role of family members in leprostigma, access to resources, social behavior and role of society towards the disease, personal outlook of individual towards illness and mental health, role of health care workers and decision making during the course of illness. Findings are summarized in Table 3.

Employment – Economic independence: All the male patients in our study were employed and earning while the female patients of leprosy were unemployed and dependent on their family members for monetary help.

Response of one 43-year-old female participant, *“Ghar me kamaane waale mere pati hi hai. Saare kharchon ke liye mujhe unhi se paise lene hote hain. Ghar se hospital aane jaane ke liye main sarvajanik aur sarkari bus ka prayog karti hu kyunki usme paise nahi lagte hain. Dawaaiyaan free hi aati hain sarkari hospital se lekin kabhi koi dawai na milne per bahar ki dispensary se khareedni padti hai . Har mahine ka kharcha hota hai aur ye dawaaiyaan to lambe samay tak khaani hoti hai. Vaise to mere pati kabhi mana nahi karte par jab aarthik tangi hoti h to kabhi kabhi ek do mahine ki dawaai nahi khareed paati hoon”. (English translation: “My husband is the only earning member in the house. I am dependant*

Table 3 : Thematic framework analysis of leprosy patients.

S. No.	Themes	Categories of themes	According to/in case of male patients	According to/in case of female patients
1.	Role of family members in leprostigma	Financial support Division of labor at home Attitude and beliefs at home and family members Medical management and physiotherapy services	• Male leprosy patients were earning and had steady source of income. They were financially independent. • Male members were the earning hands and did most of the outside jobs like ration collection and buying daily utility needs, bearing expenses of children and family. • Husbands and wife share mutual empathy with their partners. Children are supportive of their parents suffering from leprosy. • Spouses and children are very supportive of their partners and parents and encourage them to take medicine and physiotherapy services timely.	• Not getting money from family members • Women depending on husbands and sons for money • Women doing household chores during active disease, reactions of leprosy. Men mostly taking rest from household and workplaces during episodes of reactions • Husbands and children are affectionate and considerate. However, mother and father-in -law are cynical and believe in past sins and karma responsible for present day suffering. • Spouses and children are very supportive. However, some family members also propose concomitant use of household remedies for shooting away episodes of reactions.
2	Access to resources for patients of leprosy	Quality of healthcare services	• Patients do not get money for transportation and services. • Long waiting hours at OPD, investigation, medicine collection and physiotherapy. • Absence of effective communication and access to services • Expenditure is within control. • Sometimes non availability of medicines at the centres. • Long time for confirmation of disease by histopathology.	• There was no discrimination as far as the quality of health care services was concerned. Female patients received same treatment and guidance from health care professionals and staff of the hospital during the management of case and reactions episodes. • Access to resources was limited as they had to depend on their family members for transport.

3.	Social behaviours/ role of society towards the disease	Social events like marriages, birth death rituals.	• Male patients with patches, deformities during episodes of reactions are still segregated and looked upon in social gatherings because of the fear of spread through contact.	• Female patients had lesser social mobility and social contacts. They suffered discrimination at the hands of relatives who maintained social distance from them due to the disease.
		Use of public transport like buses, trains, aircrafts.	• No discrimination observed during travel through any modes of public transport.	• No discrimination observed during travel through any modes of public transport.
		Behaviour at workplaces.	• No discrimination at workplaces in behavior. However daily wages, pay and promotions suffer due to frequent leaves during the course of illness and episodes of reactions.	• As the lady patients were mainly unemployed, they did not suffer any such problems.
		Behavior at public places and places of recreation like hotel, restaurants, theatres, zoo	• No discrimination at public places by general masses probably due to fear of social rules, right to freedom of individual and equality in services.	• There was no discrimination at public places.
4.	Personal outlook of individual towards illness and mental health.	• Anxiety, insomnia, depression, fear of segregation, adjustment problems and low self-esteem due to disease and reactions.	• Mental health suffers during the process of disease detection. • Anxiety and depression with low self–esteem persists throughout the course of illness that worsens during episodes of reactions. • Feeling of segregation. • Sometimes suicidal thoughts come to end life full of misery.	• There is depression and lack of certainty about the future. As a lady there is additional responsibility of husband children and in-laws. • Lack of sleeping hours due to insomnia

5.	Outlook of health care workers towards leprosy patients	Doctors, nurses, paramedics, physiotherapists	• Doctors take time to see patients and also explain about the disease progression and end of treatment. • Waiting period is long to meet the doctor and medicine collection. • Staff is supportive soft-spoken and friendly. • Physiotherapists teach exercises and explain the correct use of splint while issuing them.	• Doctors, staff and nurses are helpful, compassionate and considerate. • Waiting period to see the doctor is long but being a lady we are given privilege.
6.	Decision making	Patriarchal nature	• Women need permission from their husbands and in laws to leave home for treatment and physiotherapy services. • There is still the need for involvement of elder members like mother-in-law for decision making.	• Women need permission from their husbands and in laws before moving out. • Mother and father-in law are the important members of the family. Each and every major decision is driven by in consultation to them.

on him for all te expenses. I use public transport to reach the hospital from home as it is free of cost. Medicines are also free from government hospital sometimes due to non-availability of medicines in dispensary I need to purchase them from outside. This is monthly expenditure as treatment has to be taken for a long duration. Although my husband never denies money but sometimes when there is paucity of funds, I have to skip medicines for a month or two).

During illness women were found to have doing daily household chores. Spouses and children were found to be very supportive of the patients.

Response from another 37-year-old female patient*, "Pati aur bachhe bahut dhyaan rakhte hain. Beemari ke dauraan kabhi kabhi bahut kamjori lagti h. Beech beech me jab laal patches nikal jaata to bukhaar bhi aa jaata h lekin phir bhi ghar ka kaam, bachon aur pati ki dekhbhaal to dekhna hi padta hai. Ghar ke saare kaam main hi karti hu. Ghar me sasu maa ka kehna hai ki bache aur pati ki jimmedaari tumhaari hi hai. (*English translation *: "Husband and children take good care of me. I feel very tired sometimes during the course of illness. In between when I develop red patches they are accompanied with fever but I still have to do daily household chores, take care of children and husband. I only do all the household jobs. my mother-in-law says that it is my responsibility to take care of husband and children").*

Access to medical care: Some patients experience long waiting hours at OPD for investigation, medicine collection and physiotherapy. The time taken for histopathology report confirmation is long. Sometimes non- availability of medicines is an issue.

Reply from a 34 year old participant *(Number 2), "Doctor ko dikhaane ke liye, dawaai lene ke liye lambi line me lagna padta hai, ghanto khade hona hota hai. Physiotherapy ke liye number lagaana hota hai. Sabhi logon ka bartaav hamaare prati acha hi hota hai. Kuch log line me aage bada dete hai taaki hum jaldi dawaai le paaye. Dawwaiyaan kabhi kabhi nahi milne par badi dikkat hoti hai phir us mahine wo dawaai nahi khaati kyunki baahar ki dukaano par bhi nahi mil paati hai. Jaanch ki report aane me bada samay lagta hai". (*English translation: *"I have to stand in long queue for long hours to meet the doctor and collect medicines. Everybody behaves nicely with us. Some people let us bypass the long queue to take our turns first so that we can get medicines early. It is very troublesome sometimes when we don't get the medicines because they are not available in outside medical shops also. It takes long time for the investigation reports also").*

Mental Health: Patients were asked to fill the questionnaire about their mental health. Most of the patients experienced anxiety, depression, lack of self –esteem and fear of segregation at the time of detection of illness. These problems are more pronounced during episodes of reactions.

Response of a 46 years old participant (number 17*", "Jab mujhe doctor ne bataya ki mujhe kushta rog hai to mujhe pehle to yakeen hi nah hua ki mujhe aisa ho sakta h, phir kaafi dino tak mujhe achi neend nahi aayi, dukhi rehne laga, ghabrahat bhi hoti thi ki ab parivaar ka kya hoga, kya mujhse ye beemari mere bachon ko bhi aa jayegi, logo se aur dost logo se milne me hichkichahat hone lagi. Pariwaar ke logo ne mujhe aur mere biwi bachon se dooriya kar lee. Hume kisi bhi shaadi samaroh me nahi bulaaya jaata tha. Mujhe bahut bura lagta tha. Phir bhi maine himmat nahi haari aur main ilaaj jaari rakha, abhi kaafi acha mehsoos karta hoon". (English translation, "When the doctor told me about my leprosy illness initially I could not believe that I could have the disease, then I felt sleepless for many days, I used to feel sad about what will happen to my family now, whether my children would also contract my disease, I was hesitated to meet friends and family. My relatives* *developed distance from me and my family. We were not invited in any occasion or gatherings. I used to feel bad about it. Then also I didn't lose hope and continue to take treatment, now I feel good").*

The attitude of society is improving in toto. There have been no social ostracizing or segregation experienced by patients in public places. But within society some people are hesitant to mingle with them during occasions of marriages and other social occasions. At workplaces they are mostly treated nicely but experience demarcation at the time of promotions.

A 36 year old participant (Participant 8) stated *: "Mujhe kabhi bhi kisi sarvajanik sthan se bhed bhaav ka saamna nahi karna pada. Bus, rail ya hawaai safar me bhi kabhi kisi ne kuch galat nahii bola ya kara. Mujhe lagta hai ki parivaar ke andar rishtedaar jyaada bhedbhaav kerte hai. Naukri me kisi ne mujhe kuch bura nahi bola lekin mera haath kaam nahi karta h isliye promotion mujhe nahi mila". (*English translation *: "I never felt any partiality in any of the public places. No one said any wrong things to me during road ,road or air travels. I feel that relatives within the family are more partial towards me. At workplace noone ever said anything to me, but i am not able to use my hand thats why i was not promoted").*

Another 27-year-old participant (number 20) stated*, "Doctors, nurses ka bartaav bahut acha hai, doctor log sab kuch bahut ache se samjhaate hain. Unke pass bahut bheed hoti hai mareejo ki lekin jab mera number aata hai to bahut hi shanti aur samajhdaari se baat kerte hain. Koi jaldi nahi karte. Beemari ke bare me mere sabhi baatein saaf bataate hain. Dawaai dene waale bhaiya bhi achi tarah se samjhaate hai ki kaunsi dawaai kaise leni h. Pehli baar jab dawaai shuru ki thi to toilet laal rang ka aaya tha, main bahut dar gayi thi lekin jab doctor ne bataya ki ye ek dawaai ka asar h to phir dar nahi laga". (*English translation*, "The behaviour of doctors and nurses is good, doctor explains everything very nicely. There is a lot of crowds waiting for the doctor but when ma turn comes, he explains everything with patience and maturity. He doesn't make haste. he explains everything about the illness. The one who distributes medicines also explains nicely about which dose needs to be taken at what time. When I started taking medicines for the first time I had red-coloured urine, I was very afraid but when the doctor explained that it's the side-effect of medicines then i was relaxed").*

Decision making: The decision making was found to be patriarchal and feudal. Many women patients still depend on their husbands and mother-in-law in decisions like initiation of therapy, regular hospital visits and investigation.

A 18 year old son of patient (Participant 43) stated*, "Humhaare ghar me sabhi faisle mere pitaaji hi lete hain. Jab meri mummy ko kushth rog hua tab meri daadi ne kaha ki gharelu upaay se ye theek ho jayega. Lekin mere pitaaji ne phir faisla liya ki mummy ko doctor ke pass jaaker dikhaye". (*English translation*: "My father takes all the decisions of our family. When my mother had leprosy my grandmother said that it can be cured with home remedies. But my father took the decision to show my mother to a doctor").*

Based on the interviews six themes were identified (Table 3), these included role of family members in leprostigma, access to resources for patients of leprosy, social behaviors/ role of society towards the disease, personal outlook of individual towards illness and mental health, outlook of health care workers towards leprosy patients and decision making. Categories of these themes and their linkage with male/ female gender are summarized in Table 3.

Discussion

Association of leprosy with stigma and related discriminatory community behaviors has been a known global phenomenon and has been widely reported in studies from India and abroad (Adhikari et al 2013a, 2013b, De Stiger et al 2000, John et al 2005). The definition of the word 'stigma' has changed over time. Focus has shifted more on the context of society and social process from the individual attributes which originally described an individual different from 'normal' people (Sermrittirong & van Brakel 2014). In our study we noticed that leprostigma is still rooted in the minds of some persons in the society due to false beliefs that define their attitude towards patients in general. Historically leprosy has been regarded as a result of punishment, curse or wrath of God. The impairments and disabilities secondary to leprosy cannot be hidden and were/ still are the source of fear and stigma among some people (Brown 2006, Try 2006).

In our study also we found that some patients face segregation and discrimination from society. They still feel inhibited while attending marriages and social functions. The participants interviewed revealed that the stigma in society is not always due to lack of knowledge of transmission of disease. Most of the participants in our study were educated and aware of the cause and transmission of the disease. The stigma and discriminations are more pronounced when patients appear distinct due to deformities, disabilities, and reactions. They look different from other people, and this is the starting point of stigma. According to Link and Phelan "people distinguish and label human differences." (Link & Phelan 2001). This is in contrast to study conducted in Nepal in which only 62.6 per cent individuals were aware of its causative agent being a bacterium, 43.8% were aware of its mode of transmission whereas 36% associated it with other irrelevant causes like bad deeds, bad blood, curse and heredity and 25.7%reported religious rituals as its treatment (Singh et al 2019).

The impact of leprosy on social life including marriage and life after marriage has been reported in a few studies. Overall, the influence of leprosy on marriage has been decreasing over years. In our study two participants confessed during the interview that their marriage has been cancelled on the grounds of suffering from leprosy and taking treatment for it. Two female patients reported that they suffered domestic violence at the hands of their husbands and in –laws due to the disease. Recent studies from the eastern region of Nepal have shown the negative impacts of leprosy on marriage such as; cancellation of marriage after knowing the leprosy status, divorce, sexual abuse, difficulty finding partners and domestic violence. In the study by Adhikari et al (2013b) cases have been described where leprosy affected persons sharing the disease as a common social phenomenon have opted for conjugal bliss on the advice of relatives after having met each other in hospital in view of added difficulties in finding marriage partners due to existing contextual and cultural factors that affect marriage (Try 2006, Adhikari et al 2013b).

Employment and job opportunities of leprosy affected persons in our study directly related to level of skill and education. The details of income and education status has been mentioned in Table 2. The participants studied mentioned in their in-depth interviews that there was no discrimination in policy at their workplaces at the time of recruitment as well as while inclusion in service. They were employed as per their proficiency at work however they did report more leaves and absence from work on account of medicine collection and investigations and particularly during periods of reactions which affected their daily wages and monthly income. One of the leprosy patients with deformities reported to be premature terminated from service on account of loss of skill as a typist and office operator. Some participants also faced delays in promotions due to the ongoing process of disease. The findings of our study were consistent with earlier studies conducted in various parts of Nepal where cases of disqualifying a leprosy affected person from employment were reported on account of inability to perform. Furthermore, in south- east region of Nepal the rooted social stigma and fear of transmission with the wound and deformities was the reason for exclusion of patient suffering from leprosy from the employment (Adhikari et al 2013b, De Stiger et al 2000). These instances appear to be few and overall, the situation seems to be changing for better.

Mental health of the patients is still a grey area and needs further work and study. Facility of a psychological counsellor was not available in the hospital where study has been conducted. None of the patients were referred to psychiatrist for medical management. However, as an author and researcher we felt the need of an allied psychologist who could provide counselling to address mental health and issues. Although no separate assessments were done by the research team through any tools, during the course of study it was observed that patients suffered from anxiety, loneliness and depression. Few patients also expressed the impulse to commit suicide at some point of illness. On further probing it came to light that this was due to lack of adequate knowledge about the course and outcome of illness. But counselling provided by the treating doctor helps in allaying anxiety and depression to some extent. Support of spouse and family members also plays a major role that helps patient steer through the traumatic experience during illness. Hence professional counsellors may play a crucial role through their services.

Conclusions and way forward:

To conclude, the present study provides important contemporary data about stigma and its impact on physical, mental and social well-being of Leprosy Affected Persons of Assam coming for treatment to this tertiary care centre. While some effect on social interactions was indicated by these interviews, impact of employment and access to services appears to be marginal. Leprosy which was once perceived to be one of the most dreadful and feared disease is now curable. This has been made possible by efforts of NLEP in partnerships with WHO as well as state governments, national and international NGOs. Now the vertical approach of health care delivery system for leprosy related services has been converted to a horizontal one. Use of information, education and counselling by treating doctors and other health care professionals have enlightened general masses and the disease is no longer concealed because of potential discrimination. Community engagement, social participation, health education and counselling interventions can go a long run in eliminating the existing gaps in knowledge and differences. More multicentric studies from across the country need to be conducted to study the current scenario of lepro stigma, presently relevant factors, and acceptable solutions to overcome these barriers.

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