

STIGMA IN LEPROSY: A QUALITATIVE STUDY OF LEPROSY AFFECTED PATIENTS AT GREEN PASTURES HOSPITAL, WESTERN REGION OF NEPAL

Bipin Adhikari^{1, 2}, Nils Kaehler¹, Shristi Raut³, Kapil Gyanwali⁴,
Robert Sedgwick Chapman^{1, *}

¹College of Public Health Sciences, Chulalongkorn University, Bangkok, Thailand

²Tropical Health Care and Research Foundation, Kathmandu, Nepal

³Faculty of Microbiology, Manipal College of Medical Sciences, Pokhara, Nepal

⁴Faculty of Public Health, Mahidol University, Bangkok, Thailand

ABSTRACT: Stigma is a social process of interpretation towards an attribute. Every illness in a society has its own set of interpretations. The consequent impacts of society towards leprosy are reflected by the level of perceived stigma in leprosy affected persons. The psychosocial impact a person has to bear in a society after the diagnosis weighs heavier than the physical afflictions it causes which does not get cured with the mere medical treatment. Understanding the deeper reasons for perceived stigma is thus essential in directing the stigma reduction programs in leprosy. Twenty 20 people affected with leprosy were interviewed in depth by using Explanatory Model Interview Catalogue and the semi-structured questionnaire. The semi-structured questionnaires were intended to explore the reasons for concealment of the disease, lowered self-esteem due to disease, perceived respect from others, impact on marriage and their experiences with leprosy. The study revealed that fear of the discrimination on disclosure of the disease was often reported. The most reported cause of fear was the strongly rooted stereotype attached to the disease. The false belief on transmission was the other mostly reported reason for the prevalent views towards leprosy and the reasons of their separation, isolation and rejection from family members, friends and society. In conclusion, the deeply rooted negative stereotypes attached to the disease, has accentuated the social process of concealment of the disease followed by the adverse consequences in leprosy affected persons. Despite that negative stereotypes attached to this disease are globally decreasing yet the remote impending fear persists. There is a need for 1) more health education programs targeting community and 2) continuing psychosocial support to the ex-leprosy and current leprosy affected persons as medical cure alone does not alleviate the vast cradle of ignorance and negative stereotypes attached to this disease.

Keywords: Leprosy, Attribute, Stereotype, Fear, Discrimination, Nepal

INTRODUCTION

Leprosy has tormented humans throughout recorded history. The earliest possible account of the disease that many scholars believe is leprosy appears in an Egyptian Papyrus document written around 1550 B.C. Around 600 B.C., Indian writings describe a disease that resembles leprosy [1,2]. Leprosy has been mentioned as “Kustha” in ancient Sanskrit writing which itself has derogatory interpretation to denote the disease [3]. Sanskrit is a root language in Indian subcontinent including Nepal [4]. Due to shared language, culture and tradition, the social interpretation of leprosy in Nepal has long been rooted to the negative stereotypes attached to the

disease. “Kor” or “Koryia” which means leprosy is the word used to scold or curse somebody in Nepali society.

Leprosy has long been known as the stigmatizing disease, the most common notion of stigma, however, still refers to people’s fear of dealing with leprosy-affected people [5]. In the event of leprosy, the disease is perceived by the health workers according to existing physical symptoms; the illness is experienced and is shaped by the socio-cultural influences of the person; and the sickness is perceived by the society and is expressed as social stigma [6]. ‘illness’ is the culturally constituted, socially learned response to symptoms that includes the way we perceive, think about, express and cope with ‘sickness’, while ‘disease’ is the technical reconstruction of sickness into terms of the

* Correspondence to: Robert S. Chapman
E-mail: rschap0421@gmail.com

theoretical system used by health practitioners [7]. The basis of stigma development has been due to the beliefs and misconception about the causes and transmission of leprosy. Leprosy has been commonly considered to be the punishment from god in many cultures [8, 9]. In India, the leprosy is regarded as the Hindu religious punishment by god for evil deeds [10]. Leprosy is considered to be sexually transmitted from prostitute and the punishment for the moral lapse in China [11]. Another common belief is that leprosy is hereditary [12, 13]. This belief is also prevalent in many different cultures including Malaysia, China, Africa and India [10, 12, 13].

In Nepal, misconception about the causes of leprosy is still prevalent. The motives for negative behavior towards the leprosy affected person were found to be the fear of infection followed by the belief that the disease was the result of both fear of god and germs. The negative attitude towards leprosy affected person is decreasing beyond doubt, the percentage of negative behavior towards leprosy affected persons before 20 years was found to be 83% compared to 52% in recent years [14]. Stereotypical views attached to leprosy are still a dominant factor in the development of stigma [15], the stereotypes which have been entangled with the Hindu culture of maintaining purity, and avoiding pollution. This means that people with leprosy are thought to be ritually unclean, contagious and punished for his past sins [16]. Due to these attached stereotypes with leprosy, the large part of the stigma emerges even by the mere diagnosis of the disease not necessarily by the development of disfigurements and disabilities [17]. In the current study, level of perceived stigma, and perspectives on the perception of stigma, were assessed in leprosy-affected persons at Green Pastures Hospital and Rehabilitation Centre.

MATERIALS AND METHODS

The study sample comprised people affected by leprosy who were undergoing treatment for leprosy reactions, ulcers, disability-rehabilitation in addition to self-care trainings at Green Pastures Hospital and Rehabilitation Centre, Pokhara Municipality in western region of Nepal. People were eligible when they were affected by leprosy, admitted to hospital, able to give consent and willing to participate. Among total of 40 leprosy patients who were invited to participate (by verbally asking in each rooms of the wards at Green Pastures Hospital and Rehabilitation Centre), only 25 of them agreed for in-depth interview. Among 25, five of them were reluctant to participate. Finally in-depth interview

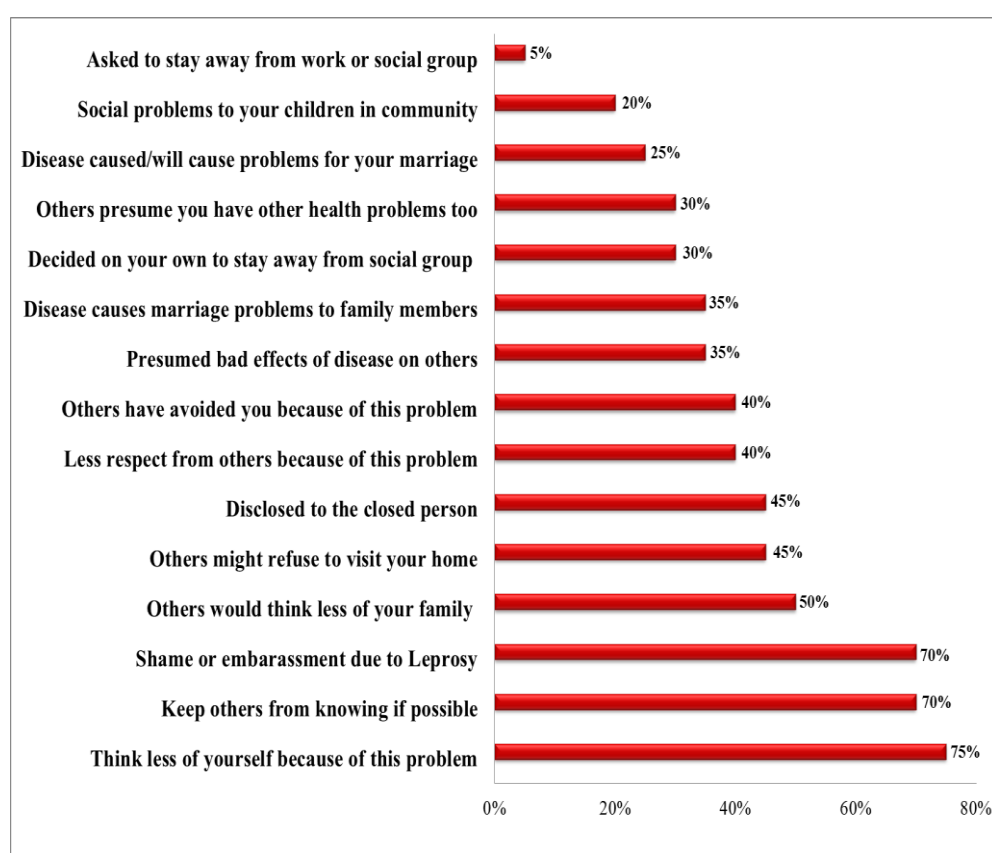
was conducted in 20 in patients. Written consent was taken with each individual before conducting in-depth interview. Interviews were conducted from February 2013 to March 2013 after an ethical permission was obtained from Nepal Health Research Council. The interview had taken into the consideration the sensitivity of the subject by establishing a friendly rapport before the session and allowing participants to express their views. Anonymity of the participants was secured by coding the participants' name. No incentives were paid.

Before the in-depth interview, Explanatory Model Interview Catalogue (EMIC) scale was used with each individual in privacy to assess the perception of the disease, their beliefs and the disease effects. Similarly, semi-structured questionnaires were asked to seek the deeper reasons for their answers to the EMIC questionnaire. Five semi-structured questions were asked to each individual to explore the reasons for concealing their disease, lowered self-esteem due to disease, perceived less respect from others, negative impacts of disease on marriage and their experiences. EMIC scale has been developed to elicit illness-related perceptions, beliefs and the practices [18]. An interview with the EMIC questionnaire and semi-structured questionnaire took 60 minutes with each individual. All the questionnaires were translated in Nepali language and Nepali language was used during in-depth interview session. EMIC questionnaire has 15 items related to perception of stigma in leprosy. EMIC scale has been both validated and reliable as evident from study in India [19]. EMIC scale has been available in different languages including Nepali language and is the recommended instrument in terms of measuring leprosy related stigma. It has been classified as the instrument to measure the perceived stigma in leprosy as recommended by The International Federation of Anti-Leprosy Association (ILEP) and the stigma research workshop held in Amsterdam in 2010 [20, 21].

Quantitative data from EMIC questionnaire and qualitative data from 5 semi-structured questions were obtained. Semi-structured questionnaire were intended to primarily answer the deeper reasons for the EMIC questionnaire. The following items were extracted out of EMIC scale in the interview-guideline: Concealment of the disease, self-esteem, respect, social attitude, impact on marriage and personal experiences with leprosy. The interviews were recorded for the reasons of accuracy after consent of the interviewees were obtained. The recorded interviews were translated back into

Table 1 Socio-demographic characteristics of the participants (n = 20)

Characteristics	Number	Percentage	Characteristics	Number	Percentage
Age group			Marital Status		
≤ 40	8	40	Single	4	20
≥41	12	60	In relationship	16	80
Mean = 46.2± 13.19			Education		
Sex			Literate	8	40
Male	12	60	Illiterate	12	60
Female	8	40	Occupation		
Ethnicity			Farmer	10	50
Upper caste	7	35	Unemployed	4	20
Middle caste	4	20	Other	6	30
Lower caste	9	45	WHO disability grades		
Location			Grade 0	3	15
Hilly region	12	60	Grade 1	5	25
Terai region	8	40	Grade 2	12	60

**Figure 1** Percentage answering “Yes” to EMIC questionnaire

English and narrative analysis was undertaken.

RESULTS

Socio-demographic characteristics of leprosy affected persons

Socio-demographic characteristics of the participants are shown below in Table 1. The mean age of the participants was 46 years with youngest age of 18 and oldest of 73. Sixty percent of them were male. Thirty-five percent of them were from

upper caste group (Brahmin and Chhetri) followed by 20% from middle caste (Gurung and Magar) and the 45% were from lower caste (minorities and dalits). Sixty percent of the participants came from the hilly regions. 80% of them were in relationship which included divorced, separated and widowed. More than half (60%) of them were illiterate. Similarly, 50% of the participants were farmer while 20% were unemployed and the other occupation group comprised private business,

student and manual workers. Majorities (60%) of them had grade II disability followed by 25% of them who had grade I disability and only 15% of them did not have any disability.

Interview with Explanatory Model Interview Catalogue (EMIC)

EMIC scale has been designed to elicit the illness related perceptions of the patient in different sensitive aspects with fine details and allied experiences. Therefore, it is indeed, valuable to assess the EMIC likert-type answers and the verification from the affected persons. The details of the EMIC profile in relation to participant's responses are presented in Figure 1.

Majorities (75%) of the participants thought less of themselves because of leprosy, followed by 70% of the participants who kept others from knowing about their disease and the same percentage of participants felt shame or embarrassment due to leprosy. Fifty percent of the participants perceived that others think less of their family while perceived refusal to visit their home was perceived by 45%. Only 45% of the participants had disclosed their disease to the close ones while perceived less respect from others and perceived avoidance was affirmed by 40%. More than one-third (35%) of the participants presumed that leprosy has bad effect on others and while same percentage of the participants perceived the marriage problems to their family members because of leprosy while only one-fourth (25%) of the participants perceived marriage problems for themselves. Social problems to their children were perceived by 20% while experience of social exclusion was affirmed by only 5%.

DISCUSSION

Concealment and disclosure

In this qualitative study, most of the persons affected with leprosy affirmed that they would prefer to conceal as long as it was possible. 14 (70%) of them said that they would rather conceal the name of the disease "leprosy" instead they would say they have some other disease in order to avoid the possible discrimination, and labeling in society, however, 50% of them confessed their disease to close ones. Most of the others, in due course of time could not conceal or were unable to hide the disease because of number of reasons like disfigurement, deformity or disclosure by some event. This was evident when asked about the concealment. The process of concealment and its cycle was as explained by Hejinders, in that most of the persons affected by leprosy did try to conceal it

at first, followed by story-telling to conceal the disease [15].

Subject 4, 43 years/female:

"They have asked me to stay a bit away in a separate place or stay not too close in gatherings like religious gatherings because of my swollen, red face. People have asked me "Why does your face look different?" I never disclosed them that it was due to leprosy or the medicine of the leprosy, rather I always told them that I have got fatter and tried to avoid the questions."

Upon asking the reasons for the concealment of the disease or the intention not to disclose about the disease, most of them affirmed that they did try to conceal and the reasons for attempt to conceal the disease were mostly the fear of transmission prevalent in both leprosy affected and unaffected persons.

Subject 10, 52 years/male:

"It is because community members and family members will discriminate. They discriminate because they are afraid that this can be transmitted to them, to the neighbors and the whole village will be transmitted."

Society fears the transmission of the disease; it bears the conventional form of the disease followed through years. Touch is still believed to be the main cause of transmission. The construction of the stigma is deeply rooted to the society, how society interprets, religious beliefs and stereotypes regarding the disease are sensitive issues that need to be addressed [22].

The fear of exclusion, separation and rejection from the society therefore, seemed the most important factor in contributing to the process of perceived stigma. The impending fear and the consequent effects of keeping the secret occupied a huge psychological burden to a patient.

Self-esteem, shame and respect from others

The decreased self-esteem (75%) and shame (70%) were found to be proportionately higher than the presumed less respect (40%) from others. The reasons for low self-esteem ranged from the fear of discrimination and separation, expected reactions from the society to the disabled conditions they acquired.

Most participants did not think they had less respect from others, however, the reasons of being less respected for leprosy affected persons were

answered based on their feelings. Most of them said that the cause of less respect was due to the visible deformities, belief that it transmits easily and the prevalent negative attitude towards the disease itself.

Most of them acknowledged the ancient practices of keeping leprosy affected persons far from home, therefore maintaining a certain distance with the affected persons and the belief that leprosy is highly transmissible might have led the fear in present context although these practices are decreasing remarkably.

The fear of transmission results in apprehension and attempt to keep distance with the affected persons which was also evidently one of the major cause for community stigma in a research conducted in eastern Nepal [14]. Recurrence of the disease, incomplete treatment, and visible wounds might have triggered the person unaffected to suspect, raise fear which consequently perpetuates the degree of negative attitudes. In contrast, perceived stigma in leprosy affected person arises out of the fear originated in the self, not necessarily with the presence of discriminatory acts [23].

Perception of the disease effects

Thirty percent of them believed that the disease would have bad effects on others. The perception itself signifies the level of knowledge and the attitude of leprosy patients towards the disease. Refusal to visit their homes and the decreased self-esteem of their family members due to disease were perceived in almost 50% of the participants while perceived problems to their children were relatively lower (20%).

The perceptions towards the disease and its social effects were still prevalent. The effects of the disease in family, religious activities and the festivals were perceived to be negative and that disease would degrade the esteem of family members was still prevalent which might have persistent impact on leprosy affected person.

Marriage and leprosy

Majority (70%) of them stated that they did not had any problems for marriage or do not expect that leprosy will cause any problems for them to get married. Similarly, 60% of them thought that leprosy will not cause any kind of problem in marriage of their family members. Nevertheless, this was perceived to be a major problem in rural areas where lack of education and stereotypes attached to the disease are prominent.

The impact of disabilities in any society is most likely to be felt when it comes to marital prospects, although the extent of which might vary by regions.

Disabilities and deformities might affect less in a case where the socio-economic conditions are better and where social positions are secured. However, this may not be the case in leprosy related disabilities which might bear more difficulties than usual because of the fear of transmission and perception of the disease in society.

Social exclusion and presumed health

The discrepancy in the felt social exclusion was much higher (30%) compared to the social exclusion acts (5%) nevertheless these aspects of stigma are much lower than the other areas of perceived stigma. This shows that perceived amount of fear and prejudice might have affected the vicious cycle of social isolation and consequent development of stigma than the real discriminatory acts.

Presumption of other health conditions in leprosy affected person was thought to be only 30% which is lower than the other aspect of perceived stigma. In a study conducted in eastern Nepal, the visibility of the deformities, disabilities and the visible signs of reactions all were found to have cumulative effects both to the affected and unaffected persons to presume presence of some other health conditions in leprosy affected persons [15].

Experiences with leprosy

14 out of 20 had bitter experiences with leprosy sometimes in their lives. Experiences attached with the leprosy are directly or indirectly attached with the course of the disease. Varied experiences were taken into account. Experiences attached with the economic burden symbolizing layered stigma, experiences of discrimination, isolation, separation and the experiences with the disabilities were the most frequent reported problems.

S19,67 years/female:

“Some people used to put thorned-tree branches to prevent me from walking towards the common trail. They asked me not to walk this trail towards Pandhero where I used to go bring water. They put thorned – tree branches on the way to Pandhero to restrict me.”

The experiences of leprosy affected persons have been reflective to the attitude of the society towards leprosy and the consequent changes in the pattern of the perception.

CONCLUSION

In this research, the predominant domains of perceived stigma affected were concealment of the

disease, low self-esteem and the shame or embarrassment due to disease. The most common reason for concealment, low self-esteem and shame or embarrassment was found to be the fear of discrimination, rejection and isolation from the society. The perceived discrimination from the society was referred to the unaffected person's fear of transmission of the disease. Therefore, most of them perceived that by concealing the disease they can live happily in their society.

The social intervention and health-awareness programs should be given equal attention while addressing the disease and its treatment. Besides, disease treatment, rehabilitation and care, focus should be meticulously given to health education and health-awareness to the society while continuing psychosocial support to the ex-leprosy patients and current leprosy affected persons to ensure the stigma free life for them.

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