

ORIGINAL RESEARCH

**ASSESSING THE PERCEIVED STIGMA TOWARDS LEPROSY AMONG ADULT LIVING CLOSE TO THE LEPROSY HOSPITAL****G. Bhuvanewari*, P. Mangala Gowri, Mrs.Nisha, Ms.Cristinal, Mrs. Sudha merry**

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Submitted on: 26.07.18;**Revised on: 22.08.18;****Accepted on: 30.08.18****ABSTRACT:**

Background: Leprosy stigma is a kind of social stigma, a strong feeling that a leprosy patient is shameful and is not accepted normally in society. It is also called leprosy-related stigma, lepro-stigma, and stigma of leprosy.

Aim and Objective: To assess the level of knowledge on leprosy among adult living near by the leprosy hospital and to assess the perceived stigma, towards leprosy among adults living close to leprosy hospital.

Research Methodology: The research approach is qualitative and Cross-sectional descriptive study design. The 200 adult people living closed to the Germen leprosy hospital Chennai was selected as study samples, and the convenient sampling techniques was used to select the study samples. Data were collected and analysed by descriptive and inferential statistics.

Results: Perceived stigma towards leprosy was found highest among participants with age 50 years or older, more than 10 years duration of stay in community close to the leprosy colony, and participants who were illiterate had higher perceived stigma and the association of level of knowledge among people who is living nearby leprosy hospital with the selected demographic variables was determined using Chi-Square test, reveals that there is no significant association between the level of knowledge and selected socio demographic variables. Similarly, perceptions about leprosy such as; difficult to treat ($P < 0.01$), severe disease ($P < 0.05$.) and punishment by God ($p < 0.01$) were significantly associated with higher perceived stigma

Key words: Leprosy, perceived, stigma

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INTRODUCTION: The public still has misconceptions about leprosy, with persistent beliefs that it is highly contagious. In the twenty-first century, agencies such as The Leprosy Mission started campaign to end these misconceptions and worked to educate people about leprosy, its causes, and how it is transmitted. They looked for people with the disease to be identified so they can be treated and limit the physical damage, as well as control contagion.¹ In the twenty-first century, effective, free treatment was available through WHO. In many parts of the world, lay people still believe the disease to be incurable.² The multi-drug therapy provided free to countries where the disease is endemic provides a reliable cure for leprosy. Stigma in leprosy is a social process of interpretation which follows labeling, stereotyping, separation, resultant discrimination and the loss of status. Begging was often the obliged work for leprosy affected person which is considered as the most disgraced occupation in Thailand.³ In Thai culture, “leprosy” and “leprosy with disability” are still translated as Khi ruan and Khi thut to degrade another person. Therefore, measurement of perceived stigma towards leprosy in community members is a significant means of reflecting the attitudes and the stereotypes attached to leprosy in a particular society.⁴ Stigma also affects the psychosocial well-being of the affected person where social consequences of leprosy can have devastating effect on their families too. A person may feel fear or ashamed which can lead to anxiety and depression.⁵

Need for the Study: In India, leprosy is still a stigmatizing condition. Leprosy-affected people are

still stigmatized by health providers and by their neighbors. Some leprosy patients have been shunned and refused treatment for their ulcers by nurse aids, resulting in delay in diagnosis and poor compliance to treatment.⁶ In a study involving leprosy affected persons conducted in Shenoyanagar, higher perceived stigma was associated with some perceptions (leprosy is difficult to treat, leprosy is highly infectious and leprosy is a severe disease), ulcers, disabilities and the resultant loss of occupation due to leprosy.⁷ However, a study concerning the community attitudes towards leprosy has rarely been done in the past. As stereotypes are prevalent in society, it is not only a significant component to shape up the stigma but is also a major element that reflects the disease interpretation in a society. Therefore, we hypothesized that there is association between the levels of perceived stigma in leprosy unaffected community members and the factors characterizing them (socio-demographic characteristics, knowledge and perceptions about leprosy).⁸ While rare researches have been done in India concerning stigma towards leprosy, few of them only have been published. Studies were conducted at eastern Nepal, stigma towards leprosy was found to be associated with fear of infection by germs, fear of curse by God and the deformity caused by leprosy. Similarly, in a study of perceived stigma among community members living close to Leprosy treatment center in western Nepal, perceptions such as “leprosy is difficult to treat”, and “is a severe disease” were found associated with higher level of perceived stigma.⁹ In Myanmar, the lack of knowledge regarding leprosy and perceptions were attributed to the stigma addressing

the urgent need of health education.¹⁰ There have been Objectives: 1.To assess the level of knowledge on leprosy among adult living near by the leprosy hospital. 2. To assess the perceived stigma towards leprosy among adult living close to the leprosy hospital. 3. To find out the association between the level of knowledge and perceived stigma with their demographic variables among adult living close to the leprosy hospital.

MATERIALS AND METHODS: The research approach is qualitative and Cross-sectional descriptive study design. The study population was people living in nearby the Germen leprosy hospital was selected in order to assess the attitudes of these people towards leprosy affected persons and the colony while they live in the same place. The social stigma in this particular context can provide the clearer picture of stigma, level of acceptance in the society and need of stigma reduction programs. The Sample who met the inclusion criteria were selected using by convenience sampling technique. The sample size is 200 adult people who are living near by the Germen leprosy hospital. A survey was carried out by the investigators. The purpose of the study was explained and informed consent was obtain from the study sample. Data was collected by interview method by using open ended questionnaire such as Demographic profile and two sets of questionnaire form with additional Explanatory Model Interview Catalogue (EMIC). The Explanatory Model Interview Catalogue (EMIC) scale questionnaire was used in each participant to assess the level of perceived stigma in leprosy. The EMIC scale has been developed to elicit illness-related perceptions, beliefs and the practices.

The EMIC questionnaire has 10 items related to perception of stigma towards leprosy. Each question is scored as “Yes = 2, Possibly = 1, No and Don't know = 0”. EMIC scale has been both validated and reliable as evident from study in India and Indonesia. The collected data were analysed by descriptive and inferential statistics.

RESULTS AND DISCUSSION: The discussion of results of data based on the objectives of the study and interpretation from Statistical analysis. The main focus of this study was to assess among the people who are living nearby leprosy hospital regarding leprosy stigma at Gremaltes hospital, Shenoy nagar, Chennai. Regarding demographic data Out of 200 samples 56% were age group of above 50 yrs, about gender 71 % were male, 71.5 %were hindu religious, 66.5% samples were married, regarding educational status 38% were secondary class, 31% samples were labor by occupation, 46.5% samples were staying for more than 10 years near by the hospital, regarding family history of leprosy 4.5% were had history of leprosy.(Tab.1) Knowledge on leprosy: Out of 200 samples 76.5% sample were aware of the information on leprosy, 44% samples were receive the source of information from health personal, 51% were know the knowledge on cause of leprosy, 81.5% were says that leprosy is very infectious disease, 86.5% accepted that it's a communicable disease, 30.5% said that leprosy is transmitted by close contact to persons, 67.55 said that leprosy is a punishment by god. Regarding signs and symptoms of leprosy 26.5% said patches with decreased sensitivity (Tab.2).

Table 1: Frequency and percentage distribution of socio-demographic variables of leprosy stigma among people living nearby Leprosy hospital. (n=200)

Demographic variables	Frequency (n)	Percentage (%)
1. Age		
a. 20-40 years	112	56
b. 40-65 years	35	17.5
c. 65 and above	53	26.5
2. Sex		
a. Male	142	71
b. Female	58	29
3. Religion		
a. Hindu	143	71.5
b. Christian	18	9
c. Muslim	39	19.5
4. Marital Status		
a. Married	132	66
b. Unmarried	58	29
c. Separated	0	0
d. Windowed	10	0.5
5. Education		
a. Illiterate	36	18
b. Primary level	30	16
c. Secondary level	76	38
d. Higher Education	58	29
6. Occupation		
a. Coolie	62	31
b. Self Business	56	28
c. Company Worker	38	19
d. House Wife	44	22
7. How many years you have living in this hospital surrounding?		
a. 1-5 years	45	22.5
b. 5-10 years	62	31
c. Above 10 years	93	46.5
8. Family history of Leprosy		
a. Yes	90	4.5
b. No	101	95.5

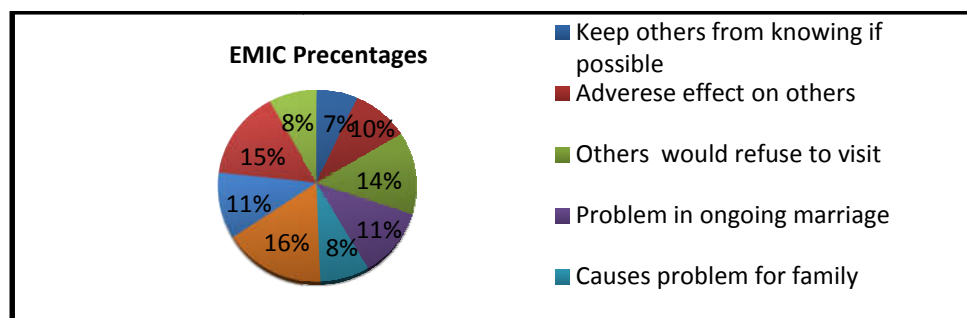
**Figure 1: Shows EMIC items of study participants answering "yes" in percentage**

Table 2: Frequency and percentage distribution of Knowledge on leprosy among adult people living nearby leprosy hospital

Sl. No	Characteristics	Frequency	Percentage (%)
1.	Received information on leprosy		
	a. Yes	153	76.5
	b. No	47	23.5
2.	Source of information		
	a. Health personal	88	44
	b. Friend or family members	67	33.5
	c. Other (TV/Radio/Paper)	45	22.5
3.	Knowledge on cause of leprosy		
	a. Yes	102	51
	b. No	98	49
4.	Source of leprosy cause		
	a. Bacteria	144	72
	b. Virus	56	28
5.	Leprosy very infectious		
	a. Yes	136	81.5
	b. No	64	32
6.	Leprosy communicable disease		
	a. Yes	173	86.5
	b. No	27	13.5
7.	Leprosy transmitted		
	a. Air	46	23.5
	b. Water	52	26
	c. food	36	18
	d. Close contact to persons	61	30.5
	e. Others(Animals/mosquito)	4	2
8.	Knowledge on signs/symptoms of leprosy	125	62.5
	a. Yes	75	37.5
	b. No		
9.	Signs and symptoms		
	a. Patches	45	22.5
	b. Patches with decreased sensitivity	53	26.5
	c. Weakness had, feet, eyelids	25	12.5
	d. Nerve pain	47	23.5
	e. Painless wounds	30	15
10.	Leprosy punishment by God		
	a. Yes	65	32.5
	b. No	135	67.5

Regarding Explanatory Model Interview Catalogue (EMIC), scores was assessed for the measurement of perceived stigma in community participants. The total median score of EMIC scale was analysed to compare between different groups. Each domain of EMIC scale has been shown with the percentage

answering “yes. 56.5% said punishment by God and (48%) participants were perceived shame or embarrassment in community due to leprosy. Similarly, dislike to buy foods from leprosy affected persons was perceived by 49.8% and difficult to find work for leprosy affected person was perceived by

47.1%(Fig.1) The association of level of knowledge among people who is living nearby leprosy hospital with the selected demographic variables was determined using Chi-Square test, reveals that there is a significant association between the and selected socio demographic veribles at the level of ($P < 0.01$) were significantly associated with higher perceived

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