

## A STUDY OF SOCIAL STIGMA BY THE NEIGHBOURS AMONG LEPROSY PATIENTS OF AGRA AND KANPUR DISTRICTS OF U.P.

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### ABSTRACT

*In the present study social stigma & discrimination was assessed among the leprosy patients by the neighbors using an interview schedule.*

**Objectives :** *To study the social stigma & discrimination by the neighbors with the leprosy patients.*

**Study Design :** *Cross-sectional.*

**Setting and Participants :** *Male leprosy Patients attending the Government OPDs, of S. N. Medical College, Agra, G.S.V.M. Medical College, Kanpur, N.J.I.L. & OMDs (ICMR), Agra, District Hospitals and 2 CHCs & 4 PHCs of the Districts of Agra and Kanpur.*

**Sample Size :** *200 registered & confirmed male leprosy patients aged 18-60 years (100 each from Agra and Kanpur Districts).*

**Results :** *It was observed that 43% (86) of the respondents became anxious after knowing about their disease and 29% became hopeless. It was also seen that 52% (104) patients could not sit freely with their neighbors and 50.5% (101) of the patients were made fun by neighbors once or twice. It was seen that 58.5% of the patients do not visit at their neighbors home after diagnosis of the disease and when they were asked the reason, 71% (83) were found self stigmatized followed by rude behavior of the neighbors (19%) while 5% of the patients were restricted by the family. It was also observed that most of the patients feel ashamed due to their disease.*

**Conclusion :** *The patients feel ashamed and self-stigmatized due to disease it is also concluded that respondents avoid to visit at their neighbour's home & their family functions due to bad behaviour of the neighbours.*

**Key words :** *Male leprosy patients, Social stigma & discrimination.*

### Introduction :

Leprosy is often called a "social disease". There are numerous social factors which favour the spread of leprosy in the community such as poverty and poverty related circumstances (e.g., overcrowding, poor housing, lack of education, lack of personal hygiene) and above all, fear, guilt and unfounded prejudices regarding the disease. (Park. K., 2007.)

As soon as people come to know that a certain individual is suffering from leprosy, the process of casting out starts. Building of a social distance starts between the patient and people. This not only affects the individual patient, his family and neighbors but also who come in contact with the patient. This social distance is expressed in many ways. Some of the patients are not invited for occasions like religious functions, social ceremonies, & other community gatherings etc. Some are refused participation in educational institutions, means of transport and communications, places of employment and also avoided for marriage. Therefore, patient is outcast first socially and later economically.

### Methodology :

Two Districts Agra and Kanpur were covered in the study. Distt. Hospitals of both the Distts., SN Medical College, Agra, GSVM Medical College, Kanpur; NJIL & OMD Agra and four P.H.Cs. and two C.H.Cs were selected from both the Districts.

200 confirmed & registered male leprosy patients between the age group of 18-60 years who were getting treatment from Govt. Health Care Centers were selected by using purposive sampling technique. The data was collected through an interview schedule by face to face interview by the author.

### Results :

In the present study it was observed that in the current scenario the social stigma is reduced but the self stigma is still developed in the patients.

Table 1  
FIRST REACTION OF THE PATIENTS AFTER KNOWING ABOUT THEIR DISEASE

First Reaction	District		Total		Statistical Values		
	Agra	Kanpur	No.	%	$\chi^2$	df	P
Will be Cured	16	14	30	15.0	4.473	4	>0.05
Became Hopeless	24	34	58	29.0			
Became Anxious	43	43	86	43.0			
Felt End of Life	9	4	13	6.5			
Fear of Boycott from the family & community	8	5	13	6.5			
<b>Total</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>100.0</b>			

Table: 1 reveals that the most common reaction after knowing about their diseases was anxiety (43%) followed by 29% (12% from Agra & 17% from Kanpur) became hopeless, while 6.5% felt that it is the end of life. The another 6.5% had fear of boycott from the family and community, Only 15% patient's reaction was that the disease will be cured completely (equal in both the Districts). Statistically insignificant different was found regarding first reaction of the patients after knowing about their disease in the two Distts. ( $\chi^2 = 4.473$ ,  $df = 4$ ,  $p > 0.05$ ).

Table -2  
NEIGHBOR'S BEHAVIOR REGARDING FREELY SITTING WITH THEM

Neighbors sit with patient freely	District		Total		Statistical Values		
	Agra	Kanpur	No.	%	$\chi^2$	df	P
Yes	28	27	55	27.5	9.843	2	>0.05
No	60	44	104	52.0			
Uncertain	12	29	41	20.5			
<b>Total</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>100.0</b>			

Table 2: shows that most of the patients 52% do not sit with their neighbours (60% from Agra and 44% from Kanpur) however 27.5% (55) patients informed that their neighbours had no problem to sit with them while 20.5% (44) did not respond about it as they were uncertain. In Agra District, 60% patients were not allowed sit with them by neighbours as compared to 44% in Kanpur District. Statistically significant different was found regarding sitting freely by the neighbours among the patients of the two Distts. ( $\chi^2 = 9.843$ ,  $df = 2$ ,  $p < 0.05$ ).

Table 3  
SUFFERING WITH UNTOUCHABILITY BY THE NEIGHBORS

Untouchability	District		Total		Statistical Values		
	Agra	Kanpur	No.	%	$\chi^2$	df	P
Yes	14	5	19	9.5	5.173	2	>0.05
No	40	49	89	44.5			
Can't say	46	46	92	46.0			
<b>Total</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>100.0</b>			

Table: 3 indicates that in the present study, there was the lesser degree of untouchability. It was observed that in Agra District, untouchability was 14% while it was as 5% in Kanpur District, the total being 9.5% only while 46% (92) did not respond about it as they were uncertain about it. Statistically insignificant difference was observed regarding the untouchability between the patients of Agra & Kanpur Districts. ( $\chi^2 = 5.173, df = 2, p > 0.05$ )

**Table 4**  
**MAKING FUN OF THE PATIENTS BY THE NEIGHBORS**

Making Fun	District		Total		Statistical Values		
	Agra	Kanpur	No.	%	$\chi^2$	df	P
Yes	42	59	101	50.5	6.433	2	>0.05
No	17	9	26	13.0			
Can't Say	41	32	73	36.5			
<b>Total</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>100.0</b>			

It was observed that most of the patients were made fun once or twice by the neighbors, table: 4 reveals that 50.5% of the patients (42% from Agra & 59% from Kanpur) were made fun by neighbors once or twice, directly or indirectly however 13.0% responded that they were not made fun of them by neighbors while 36.5% (41% from Agra & 31% from Kanpur) did not respond about it. Fun making of leprosy patients was more common in District Kanpur than Agra (59% & 42% respectively). Statistically significant difference was observed regarding fun making of the patients by the neighbors among the two Distt. ( $\chi^2 = 6.433, df = 2, p < 0.05$ ).

**Table 5**  
**PATIENTS VISITING NEIGHBOR'S HOME**

Patients Visiting Neighbor's Home	District		Total		Statistical Values		
	Agra	Kanpur	No.	%	$\chi^2$	df	P
Yes	44	39	83	41.5	0.515	1	>0.05
No	56	61	117	58.5			
<b>Total</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>100.0</b>			
<b>If yes, the behavior of neighbors :</b>							
As before	29	12	41	49.0	17.095	2	>0.05
Bad than before	9	5	14	18.0			
Normal	6	22	28	33.0			
<b>Total</b>	<b>44</b>	<b>39</b>	<b>83</b>	<b>100.0</b>			
<b>If no, the reason :</b>							
Self Stigmatized	31	52	83	71.0	12.386	2	>0.05
Rude behavior of the neighbors	15	7	22	19.0			
Restricted by the patient's family	6	0	6	5.0			
Other	4	2	6	5.0			
<b>Total</b>	<b>56</b>	<b>61</b>	<b>117</b>	<b>100.0</b>			

In the present study it was observed that patients were self stigmatized, as the patients did not use to go at their neighbor's home due to their disease because they feel guilty and feel as being past sinner. Table: 5 indicates that 58.5% (117) of the patients do not visit at their neighbor's home but rest 41.5% (83) used to visit after the diagnosis of the disease.

Out of 83 patients who used to visit at their neighbors, 49% told about same behavior followed by 33% informed about normal/so so behavior, rest 18% (9 from Agra & 5 from Kanpur) responded about bad behavior by the neighbors. Statistically significant difference was observed regarding the behavior of neighbors between the patients of both the Districts. ( $\chi^2 = 17.095$ ,  $df = 2$ ,  $p < 0.05$ ).

Out of 117 patients who did not go to their neighbor's home after diagnosis of the disease when asked about the reason, it was found that 71% (83) were self stigmatized followed by 19% who responded about rude behavior of the neighbors while 5% (6) of the patients were restricted by their family members. Statistically significant difference was observed regarding the reason of not to visit at neighbor's home between the patients of both the Distt. ( $\chi^2 = 12.386$ ,  $df = 2$ ,  $p < 0.05$ ).

**Table 6**  
**FEEL ASHAMED DUE TO HAVING THE DISEASE**

Feeling of Ashamed	District		Total		Statistical Values		
	Agra	Kanpur	No.	%	$\chi^2$	df	P
Yes	79	71	150	75.0	1.707	1	>0.05
No	21	29	50	25.0			
<b>Total</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>100.0</b>			

Most of the patients 75% (150) informed that they feel ashamed due to disease while 25% (50) do not feel so about it. Statistically insignificant difference was observed ( $\chi^2 = 1.707$ ,  $df = 1$ ,  $P > 0.05$ ) among the patients of two Districts in this regard.

**Discussion :**

Carcianiga (2006) and Coveying - Kwong Kam H.C. et.al. (2001) observed in their studies "Stigma is a major social complication from leprosy." Leprosy is considered to cause more social than medial problems. Ogden JA, et.al. (1999) observed in their study that "leprosy is now a disease that can be treated and cured, but it is stigmatized." Carol Shieh (2006) agreed that it is surrounded by myth, fear, and by isolation. The present study focused on this aspect in order to investigate the level of social stigma. Lesser degree of untouchability was observed in the present study. The study shows that out of total patients only 9.5% (19) were suffering with untouchability. Kushwah S S. et. al. (1981) conducted a study and estimated that 57 (62.64%) cases told that they have social stigma on touch while minimum i.e. 9 (9.89%) cases were having social stigma of speech. But in the present study it was observed that neighbors do not sit with the patients as freely as before the diagnosis/disclosure of the disease, 52% of the patients told that the neighbors do not sit with them freely, while about 50% of the patients informed that they are made fun by the neighbors once or twice, directly or indirectly. However a high level of self - stigmatization among the patients was observed, most patients (58.5%) don't visit at their neighbor's home after diagnosis of the disease because 71% (83) of them were self-stigmatized & 19% don't go to the neighbors home due to rude behavior of the neighbors. In similar studies conducted by Myint T, Ulrich M & Kumaresan JA. they concluded that many leprosy patients

also experience rejection from the societies and are not able to find complement.

In other studies of Bakirtzief Z. & Bijleveld I. it was observed that the health- care seeking behavior of people is affected by leprosy which is influenced by many factors, including the patients and the society's beliefs and perceptions about leprosy, the availability, accessibility acceptability and affordability of health services quality of the health care provider - patient relationship and the patient's socio-demographic characteristics. In a society which discriminates against leprosy sufferers, the patients would conceal their condition and will not seek or adhere to the treatment for fear of or as a result of social rejection.

Myint T., Ulrich M & Kant V. P. observed in their study that Persons affected by leprosy experience enzymatic reactions, insults and rejection from society. The stigmatization in leprosy is frequently extended to the families having suffering from leprosy. Kopparty SN. in their study revealed that the families with a patients who had deformities faced 10 times higher society problems than those having patients with no deformities.

**Belief about the causation of leprosy :**

Beliefs about the causation of leprosy have differed over time and between places. These beliefs affect how the disease and those who have it are perceived. Some groups believe that leprosy is caused by bad blood, contact with leprosy patient & the God's or the Goddess discretion for wrongdoing either in

this or a previous life; there is a complex mix of reasons why leprosy is a feared and shameful disease. Those affected with leprosy are avoided as they are seen sinful, and those around them do not themselves want to incur that wrath.

#### Conclusion :

The behaviour of the neighbours is not good with the leprosy patients, the patients avoid to attend the family functions of their neighbours, do not go to their homes because the neighbours do not feel comfort with the patients, they avoid to sit with them so the patients feel ashamed and they were self stigmatized. Self-stigmatization is a very real issue. People with leprosy may become ashamed, possibly because of local attitudes and deformity, and may isolate themselves from society thus perpetuating the idea that leprosy is something shameful to be hidden away. The self-loathing associated with leprosy can be permanent; persisting even after the disease is cured.

The status of stigma has been changed in the present scenario. The social stigma is reduced but the high level of self-stigmatization was observed in the study.

There is an urgent need for better education and more effective Health Education of the patients as well as the community regarding all aspects of leprosy.

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