

Awareness of Leprosy - Knowledge and Perception Among People Affected by Leprosy in an Endemic District, West Bengal, India

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Leprosy continues to be a public health concern primarily because of its potential to cause physical disability, social stigma and discrimination, even for those who have been cured completely. This study attempts to explore the awareness of leprosy among the people affected by leprosy reporting at leprosy referral centre, Purulia, West Bengal, India. A cross-sectional study was conducted among 358 people affected by leprosy aged above 18 years. A semi-structured interview schedule was prepared to assess the awareness about leprosy which includes their knowledge and perception about the disease. Findings indicate that out of 358 respondents, 94% did not know the cause and mode of transmission of leprosy, 74% knew about the symptoms, 35% believed it as infectious disease and 84% opined that the disease was curable. Among them, 44%, 57% and 18% believed that the disease was chronic, life threatening and hereditary respectively. Most of the respondents (97%) considered allopathy as the most preferred mode of treatment and 60% believed that the deformity due to leprosy was correctable. This study manifests that the knowledge about the causes and modes of transmission of leprosy was not adequate among the affected people. However, they have knowledge about the symptoms and believe that the disease is curable by allopathy medical intervention. Improving the knowledge about the disease could positively reduce the inhibition and stigma about the disease which will also enhance the possibilities of early reporting and early detection.

Keywords : Leprosy, Knowledge, Perception, Disability, Purulia.

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* (WHO n.d). It is still a public health concern primarily because of its potential to cause physical disability, social stigma and discrimination (Noordeen 1995, ILEP 2002), even for those who have been cured completely

(Mankar et al 2011). Psychological impact on sufferers and their families is well known (Singh 2012).

In India, misconceptions about leprosy are still prevalent (Singh et al 2013, Pradhan & Kumar 2016). In spite of the fact that leprosy is completely curable by multi-drug therapy (MDT),

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the negative attitude towards the disease still persists (Saha et al 2015, Seshadri et al 2014, Stephen et al 2014, Mankar et al 2011). A study done in India reported that many people believed that leprosy is transmitted through sharing food and drinks, utensils, contact with the diseased person's sweat, mosquito or insect bites and sexual contact with a person with leprosy (Singh 2012). Some people alleged that leprosy is a disabling disease that is incurable, hereditary, and associated with dirtiness, oozy and bad smelling wounds (Sermittirong et al 2015). Besides, the people affected by leprosy and community members were still not sure about the cause of leprosy (Myint 1992).

In India, a total of 1,35,485 new cases were detected during the year 2016-17, with a prevalence rate (PR) of 0.66 per 10,000 population as on 1st April, 2017 (NLEP (a), 2017). Leprosy is still prevalent in certain parts of India including Purulia district in West Bengal where elimination of the disease still remains a concern. As on March, 2017 Purulia district has a high prevalence rate (PR) of 2.37 in 10,000 populations, and annual new case detection rate (ANCDR) stood at 52.47 in 100,000 populations (NLEP (b) 2017).

Awareness is the state or condition of having knowledge or consciousness. The Oxford dictionary defines awareness as "knowledge or perception of a situation or fact" (Lexico 2020). Awareness about leprosy and its symptoms remain indispensable for early reporting and early detection. Early detection will prevent the deformities and disease transmission. Knowledge is an important factor to determine the attitude towards the disease and it is determined by the social, environment and cultures of the people. Hence, this study makes an attempt to explore the contemporary knowledge and perception about the disease among people affected by leprosy in Purulia district, West Bengal.

Methods

The study took place in a tertiary leprosy referral hospital, Purulia, West Bengal, India from April to June 2017. An Institutional based cross sectional study design was used. All adult persons affected by leprosy, aged above 18 years, married, diagnosed at least one year before the time of interview, who were willing to participate and those who gave written informed consent, were included, and those Individuals living in leprosy colony were excluded.

Patients' registration database for last five years was obtained from the medical records department of the institute and the details of the adult patients (aged above 18 years), who visited the hospital for treatment were extracted to determine the sample size. On an average, 3430 patients visited the institution every year for treatment and it was rounded off to 3500 patients, to determine the sample size. The sample size was determined by using open source epidemiologic statistics for public health (Dean et al 2013), by assuming 5% marginal error, 95% confidence interval ($\alpha=0.05$), and the proportion of 50%. Result showed that the required sample size for the study was 347 respondents.

Semi-structured interview schedule was prepared after review of relevant literature. The questionnaire was divided in three parts (1) used to assess the demographic and disease profile of the respondents, (2) used to assess knowledge about leprosy of the respondents; and (3) assess the perception towards leprosy and people affected by leprosy. Perception about the illness was measured by using the 11 point numerical rating scale and it ranges from '0' to '10' (De Vaus 2013). It is categorized as poor understanding (0), minimal (1-3), moderate (4-6) and good (7-10) for analysis.

Before the data collection, participants were informed about the study objectives, data collection process, and consent was taken for their participants in study. The interview schedule consisted of information about present demographic and disease status followed by details on affected person's knowledge and perception towards the disease. All interviews were conducted in vernacular language 'Bengali'. The interview was conducted in strict privacy after building rapport with the respondents and necessary precaution was taken to avoid emotional distress of participants. In case of the emergence of any emotional distress, the interview was terminated and counselling was given.

The entire data collected was entered in Microsoft excel and analysed by using SPSS. The data was presented by using frequency tables and narrative texts. Chi-square test was done at 5% level of significance and p-value was used to observe the statistical significance association between variables. Ethical clearance was obtained from Doctoral Research Committee members, Department of Sociology, Bharatidasan University and The Research Ethics Committee of The Leprosy Mission Trust India, New Delhi. Participation was voluntary and information was collected anonymously after obtaining written consent from each respondent by assuring confidentiality throughout the data collection period.

Results

Details of demographic profile, disability status and disease duration of the participants are described in Table 1. Of the 358 participants, 41% of them were females, 60% were aged between 18-45 years, 58% were literate and 55% of them were labourers or farmers. Hundred and sixty-seven (47%) were living in medium size families and 75% of their monthly family income was

Table 1 : Demographic profile and disease status of the respondents (n=358)

Status	Frequency	Percent
Gender		
Male	212	59.2%
Female	146	40.8%
Age		
18-30 years	69	19.3%
31-45 years	145	40.5%
46-60 years	111	31.0%
Above 60 years	33	9.2%
Education		
Illiterate	207	57.8%
Literate	151	42.2%
Occupation		
Labour	99	27.7%
Farmer	96	26.8%
House wife	135	37.7%
Others	28	7.8%
Family Size		
Small Family	128	35.8%
Medium Family	167	46.6%
Large Family	63	17.6%
Family Income		
Below Rs.5,000	270	75.4%
Above Rs.5,000	88	24.6%
Disability Grade		
Grade 0	150	41.9%
Grade 1	64	17.9%
Grade 2	144	40.2%
Disease duration		
1 to 3 years	144	40.2%
3 to 5 years	112	31.3%
Above 5 years	102	28.5%

below Rs. 5,000. More than half of them (58%) had physical impairment (grade 1:18% and grade 2: 40%) and 60% of them lived with the disease for more than three years.

Knowledge about leprosy

Of the 358, 336 (94%) respondents did not know about the cause of leprosy, 226 (74%) of them knew about the symptoms of leprosy, and 335 (94%) of them did not know about modes of spreading of the disease. Hundred and twenty-six (35%) respondents reported that leprosy is an infectious disease and 141 (39%) of them reported as non-infectious disease. Three hundred and one (84%) respondents opined that the disease was curable and 270 (61%) of them said that the deformity, due to leprosy, can be rectified by surgery, medicine, exercise, massage and regular treatment. Hundred and eighty-six (52%) of the respondents have seen people affected by leprosy, before the diagnosis of disease and 198 (55%) were willing to know more about the disease after the diagnosis of disease. Three hundred and forty-eight (97%) respondents

considered allopathic treatment as the most preferred mode of treatment. The reason for their preference of allopathic treatment, as the choice for leprosy was their belief that allopathic treatment can cure the disease quickly and results were better than the other available treatments in India (Table 2).

Perception towards the disease of leprosy

Of the 358 respondents, 158 (44%), 205 (57%) and 229 (64%) felt that leprosy was a chronic disease, life threatening and not hereditary respectively. When it comes to the perception of recovery from the disease, 153 (43%) of them said that they would recover completely. Hundred and two (29%) of them reported that the people affected by leprosy must go for regular treatment and 124 (35%) respondents said that they feel pity, helpless, sorrowful and fear of having same condition. Overall, when it comes to the

Table 2 : Knowledge about the Disease (n=358)

Knowledge	Frequency (n)	Percent (%)
Do you know how leprosy causes?		
Bacterial disease & germs	13	3.6%
Air pollution, spreads from affected person & sharing food	9	2.6%
Not know	336	93.9%
Do you know about the symptoms of leprosy?		
Know	266	74.3%
Not know	92	25.7%
Do you know how leprosy is spreading?		
Air and dirty place	7	2.0%
Touching and things used by the affected person	7	2.0%
Sneezing & coughing	5	1.4%
Water, sharing food, sweating, blood	4	1.1%
Not know	335	93.6%
Do you think leprosy is an infectious disease?		
Infectious	126	35.2%
Non infectious	141	39.4%
Not know	91	25.4%

Do you think leprosy is curable?		
Curable	301	84.1%
Not curable	29	8.1%
Not known	28	7.8%
Do you think deformities due to leprosy can be preventable?		
Prevent by surgery, medicine, exercise and massage	84	23.5%
Prevent by medicine	79	22.1%
Prevent by medicine, massage and exercise	54	15.1%
Not preventable	31	8.7%
Not know	110	30.7%
Have you ever seen anyone having leprosy before you diagnosed?		
Seen	186	52.0%
Not seen	172	48.0%
What do you know about leprosy before diagnosis?		
Skin disease	17	4.7%
Dangerous disease and caused deformity	8	2.2%
Curable disease	2	0.6%
Not aware	331	92.5%
What more you learn about the disease after diagnosis?		
Treatment	92	25.7%
Causes and Symptoms	79	22.1%
Curable	13	3.6%
Deformity and weakness	14	3.9%
Not willing to learn about the disease	160	44.7%
What type of treatment you would prefer/suggest for leprosy?		
Allopathic	348	97.2%
Homeopathy	9	2.5%
Ayurvedic	1	0.3%

perception of understanding about their illness, 143 (40%) of the respondents perceived minimal understanding and 114 (32%) recorded moderate understanding about their illness (Table 3).

Association of knowledge of leprosy with gender differences and disability grade

Apart from the association of the knowledge and awareness, gender difference found to be yet another significant influence on the knowledge

and awareness about leprosy; The responses “is infectious disease”, “it can be preventable”, “is a chronic disease”, and “recovered completely from illness” manifested significant difference between male and female respondents (Table 4). Respondents from the disability grade have shown significant association in the response that “deformities due to leprosy can be preventable” (Table 5).

Table 3 : Perception about the leprosy disease

Perception	Frequency (n)	Percent (%)
Do you think leprosy is a chronic disease?		
Chronic disease	158	44.1%
Not a chronic disease	117	32.7%
Not known	83	23.2%
Do you think leprosy is a life threatening disease?		
Threatening	205	57.3%
Not a threatening	130	36.3%
Not known	23	6.4%
Do you think leprosy is hereditary disease?		
Hereditary	64	17.9%
Not a hereditary	229	64.0%
Not known	65	18.2%
Do you feel that you have recovered completely from your illness?		
Recover completely	153	42.7%
Not recover completely	191	53.4%
Not known	14	3.9%
What you think about the leprosy affected person?		
Must go for regular treatment	102	28.5%
Feel pity, bad, sorrow and fear of having same condition	124	34.7%
Must be cured earlier and pray for their recovery	24	6.8%
People should believe the doctor	9	2.5%
Stay away from the affected person	4	1.2%
No opinion	95	26.5%
How well you understand about your illness?		
Poorly understood	48	13.4%
Minimally understood	143	39.9%
Moderately understood	114	31.8%
Good understanding	53	14.8%

Association in perception of understanding about the respondents' illness

There is no significant association found between perceptions about the respondents' illness with the gender and disability grade. Both male and female respondents with disability grade '0', '1' and '2' had similar perception about their illness.

Discussion

The present study explored the knowledge and perception about leprosy among the people affected by the disease. Studies from India found that the most frequently known symptom of leprosy was painless discoloration of skin patches and numbness, followed by an ulcerative lesion

Table 5 : Association between disability grade and knowledge & perception of leprosy (n=358)

Gender	Knowledge and Perception on leprosy							Chi-square	p-value
	Yes	No	Don't know	Total					
Do you think leprosy is curable?									
Male	173	81.6%	23	10.8%	16	7.5%	212	5.276	0.07
Female	128	87.7%	6	4.1%	12	8.2%	146		
Total	301	84.1%	29	8.1%	28	7.8%	358		
Do you think deformities due to leprosy can be preventable?									
Male	136	64.2%	24	11.3%	52	24.5%	212	11.824	<0.01
Female	81	55.5%	7	4.8%	58	39.7%	146		
Total	217	60.6%	31	8.7%	110	30.7%	358		
Do you think leprosy is a chronic disease?									
Male	99	46.7%	82	38.7%	31	14.6%	212	22.932	<0.01
Female	59	40.4%	35	24.0%	52	35.6%	146		
Total	158	44.1%	117	32.7%	83	23.2%	358		
Do you think leprosy is a life threatening disease?									
Male	113	53.3%	87	41.0%	12	5.7%	212	5.092	0.08
Female	92	63.0%	43	29.5%	11	7.5%	146		
Total	205	57.3%	130	36.3%	23	6.4%	358		
Do you think leprosy is hereditary disease?									
Male	35	16.5%	143	67.5%	34	16.0%	212	2.817	0.25
Female	29	19.9%	86	58.9%	31	21.2%	146		
Total	64	17.9%	229	64.0%	65	18.2%	358		
Do you feel that you have recovered completely from your illness?									
Male	77	36.3%	126	59.4%	9	4.2%	212	8.761	<0.05
Female	76	52.1%	65	44.5%	5	3.4%	146		
Total	153	42.7%	191	53.4%	14	3.9%	358		

on foot (Singh et al 2013, Srivastava et al 2011). Atre et al (2011) done a study in India and observed that 75% of respondents affected by leprosy, did not know the cause of their illness. Similarly studies in India found that, people with leprosy believed that leprosy was only a disease of deformity which leads to disfiguration or bodily deformation (Singh et al 2013), and also almost all respondents affected by leprosy and community members believe that leprosy is curable (Barkataki et al 2006).

In the present study, it is witnessed that almost all the respondents did not know the cause of leprosy or the modes of transmission of the disease. However, majority of them knew about the symptoms of leprosy; anaesthetic patch, muscle weakness, nerve thickness, nodule and tingling sensation in hands and foot. Majority of the respondents opined that the disease is curable and they reported that the deformity due to leprosy can be preventable by surgery, medicine, exercise, massage and regular treat-

Table 4 : Association between gender and knowledge & perception on leprosy (n=358)

Disability Grade	Knowledge and Perception on leprosy						Chi-square	p-value	
	Yes	No	Don't know	Total					
Do you think leprosy is curable?									
Grade '0'	128	85.3%	11	7.3%	11	7.3%	150	8.719	0.07
Grade '1'	60	93.8%	1	1.6%	3	4.7%	64		
Grade '2'	113	78.5%	17	11.8%	14	9.7%	144		
Total	301	84.1%	29	8.1%	28	7.8%	358		
Do you think deformities due to leprosy can be preventable?									
Grade '0'	84	56.0%	10	6.7%	56	37.3%	150	12.194	<0.05
Grade '1'	38	59.4%	3	4.7%	23	35.9%	64		
Grade '2'	95	66.0%	18	12.5%	31	21.5%	144		
Total	217	60.6%	31	8.7%	110	30.7%	358		
Do you think leprosy is a chronic disease?									
Grade '0'	65	43.3%	51	34.0%	34	22.7%	150	6.02	0.17
Grade '1'	26	40.6%	16	25.0%	22	34.4%	64		
Grade '2'	67	46.5%	50	34.7%	27	18.8%	144		
Total	158	44.1%	117	32.7%	83	23.2%	358		
Do you think leprosy is a life threatening disease?									
Grade '0'	79	52.7%	61	40.7%	10	6.7%	150	4.068	0.40
Grade '1'	36	56.3%	22	34.4%	6	9.4%	64		
Grade '2'	90	62.5%	47	32.6%	7	4.9%	144		
Total	205	57.3%	130	36.3%	23	6.4%	358		
Do you think leprosy is hereditary disease									
Grade '0'	32	21.3%	92	61.3%	26	17.3%	150	7.615	0.11
Grade '1'	8	12.5%	38	59.4%	18	28.1%	64		
Grade '2'	24	16.7%	99	68.8%	21	14.6%	144		
Total	64	17.9%	229	64.0%	65	18.2%	358		
Do you feel that you have recovered completely from your illness?									
Grade '0'	71	47.3%	75	50.0%	4	2.7%	150	3.546	0.47
Grade '1'	26	40.6%	36	56.3%	2	3.1%	64		
Grade '2'	56	38.9%	80	55.6%	8	5.6%	144		
Total	153	42.7%	191	53.4%	14	3.9%	358		

ment. Furthermore, male respondents had more belief that the deformity could be preventable than the female respondents. The respondents who had disability grade '2' have believed that the deformity could be prevented by medicine and

surgery than the respondents with disability grade '0' and grade '1'.

Lira et al (2012) in a study with persons affected by leprosy in Brazil, revealed that half the people heard about leprosy before knowing that they

were sick. Further, the study found the prevalence of low degree of treatment adherence, despite the persons claiming to be familiar with leprosy and its treatment because they were not aware of the principles of therapy. In this study, almost all of them had no idea about the nature and severity of the disease before diagnosis. However, only around half the respondents were willing to know more about the disease after the diagnosis of the disease. Allopathy was the generally preferred mode of treatment for leprosy and it was proved in this study as many of the respondents reported that the allopathy treatment cured quickly and results were better than the other available treatment in India.

Leprosy, is not a life-threatening disease, but if not treated properly at the early stage, it can cause severe disfiguring in some parts of the body. Also, it is not a hereditary disease. Singh et al (2013), in a study with persons affected with leprosy in Chandigarh, India, observed that 'leprosy' was perceived to be a curse of God, resulting from the wrong deeds committed sometime in the past or present life. Stereotypes, resulting from Indian religious beliefs, have long focused on passivity, inferred from beliefs in fate and karma. In the present study, around half of them were still perceived that leprosy is a chronic disease and life threatening. However, two-third of them perceived that the disease was not hereditary and had a mixed feeling that they would recover or would not recover completely. The female respondents had felt more that they recovered completely from their illness than the male respondents. Around half of them had manifested moderate to good understanding about their illness. Both male and female respondents and the respondents with or without disability similarly understood their illness as well.

Accordingly, World Health Organisation and NLEP, India has stressed, leprosy is curable and early

case detection can minimise or prevent disability. WHO launched a new global strategy for leprosy in 2016; to stop disease transmission, and to achieve a world free of leprosy (WHO 2016). Target is now a leprosy free world (WHO 2019). To achieve this goal, empowerment and partnership among all stakeholders is essential. Health education is the key to provide information to affected persons and the general public, to avoid misconceptions about the disease and to increase positive attitude towards the disease and affected people. The NLEP India have been working continuously to improve awareness about leprosy among people through information, education and communication (IEC) activities (NLEP (a,b) 2017).

The study was conducted with the large sample size and assessed the knowledge, and perception with validated questionnaire. Due to resource and time limitations, the study was conducted as a cross-sectional study in a tertiary leprosy referral centre which is treating and rehabilitating the people affected by leprosy for more than hundred years and hence the findings may not be representative of other areas. Therefore, further comparative research is required to be undertaken on knowledge and perception towards the leprosy and people affected by leprosy. Future studies will need to investigate as interventional studies.

Conclusion

The knowledge on causes, and mode of transmission of leprosy was poor among the people affected by the disease. However, they have knowledge about the symptoms and believe that disease is curable by allopathic treatment and understood that deformity can be prevented or corrected by medicine and surgery. Still people believed leprosy is a life threatening disease and half of them felt that they recovered completely from their illness. The people affected by leprosy

have positive attitude towards other people affected by the disease.

To sustain the control or elimination of the leprosy, it is very important to have basic knowledge about the disease. Improving the knowledge, awareness, and perception about the disease could improve positive attitude towards the disease and it will enhance the possibilities of the early reporting and early case detection. Early diagnosis not only cures leprosy but also minimizes and prevents disability and breaks the chain of disease transmission.

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